Published in final edited form as:

J Autism Dev Disord. 2018 May ; 48(5): 1623–1639. doi:10.1007/s10803-017-3394-8.

In Search of Culturally Appropriate Autism Interventions: Perspectives of Latino Caregivers

Michaela DuBay, M. Ed., CCC-SLP, Linda Watson, EdD, CCC-SLP, and Wanqing Zhang, PhD, MD

University of North Carolina at Chapel Hill, Department of Allied Health Sciences

Abstract

Most evidence-based autism spectrum disorder (ASD) interventions are tested with primarily White, mid-upper class, English-speaking populations, despite the increase in Latino children with ASD in early intervention programs throughout the United States. Unfortunately, interventions that are incongruent with a target population's culture may be relatively ineffective. This mixed-methods study explored how culturally appropriate, feasible, and acceptable Latino caregivers perceived intervention models, strategies, and targets. Survey data were compared for 28 Latino and 27 non-Latino White parents of young children with ASD. Further, 20 Latino caregivers participated in focus groups to describe their challenges, perspectives and preferences for intervention strategies and models, and unmet needs from providers. These findings underscore the need for culturally modified interventions for Latino children and families.

Keywords

Latino; parent perspectives; cultural adaptation; evidence-based practices

Early intervention using research-based practices can improve developmental outcomes in children with autism spectrum disorder (ASD; Rogers & Vismara, 2014; Woods & Wetherby, 2003). As the largest and fastest growing minority population in the United States, Latino children comprise an increasingly significant proportion of children served in early intervention programs (Technical Assistance and Dissemination Network, 2011). Similarly, many other countries are experiencing parallel demographic changes due to high rates of global immigration. However, most early intervention research is carried out with White, mid to upper-class, monolingual English-speaking samples (Baranek et al., 2015; Roberts & Kaiser, 2011; Rogers et al., 2012; Wetherby et al., 2014). Unfortunately, research-based ASD interventions designed for and tested with White, mid to upper-class,

Correspondence concerning this article should be addressed to Michaela DuBay, Michaela_dubay@med.unc.edu, 321 S Columbia St. Chapel Hill, NC, 27516, (919) 966-9466.

Michaela DuBay, University of North Carolina at Chapel Hill, southeast, United States. Linda Watson, University of North Carolina at Chapel Hill, southeast, United States. Wanqing Zhang, University of North Carolina at Chapel Hill, southeast, United States. No changes in author affiliation subsequent to the time of the study.

Author contributions:

MD contributed to the conception and design of the study, completed data collection, analyzed and interpreted the data, and drafted the manuscript; LW contributed to the conception and design of the study, assisted with the interpretation of results, and critically revised the manuscript; WZ contributed to the analysis of results and critically revised the manuscript.

monolingual English-speaking children may not be as effective for groups differing in language or culture, including Latino families and children (Buzhardt, Rusinko, Heitzman-Powell, Trevino-Maack, & Mcgrath, 2015; Elder, Valcante, Won, & Zylis, 2003; Zayas & Rojas-Flores, 2002). Providing diverse families of children with ASD with the most effective and culturally appropriate services requires adaptations to current evidenced-based interventions or the creation of new interventions. This must be accomplished in collaboration with family members from the target community in order to draw upon a comprehensive understanding of common experiences, perceptions, and values about parenting, education, and intervention.

Parent-Mediated Intervention

Parent-mediated intervention, or teaching parents to use therapeutic strategies with their children, is a frequently studied family-centered model that could be effective for Latino families in the United States or elsewhere. It has the potential to be more cost-effective and beneficial than clinician-mediated intervention (Koegel, Schreibman, Britten, Burke, & O'Neill, 1982) as it allows caregivers to work with their children frequently and effectively in a variety of natural environments, contributing to better generalization of skills over time. Considerable evidence suggests that parent-mediated interventions, preferred by some families (Fontil & Petrakos, 2015), can be successful in treating ASD (McConachie & Diggle, 2007; Patterson, Smith, & Mirenda, 2011; Roberts & Kaiser, 2011; Rogers et al., 2012). Replicated evidence of associations between parent behaviors and later child development has formed the foundations of many parent-mediated intervention programs (Mahoney & Perales, 2003; Siller & Sigman, 2008; Tamis-LeMonda, Bornstein, & Baumwell, 2001), yet these associations were identified in studies involving mostly White, mid to upper-class, monolingual English-speaking families. Further, much of the work evaluating the efficacy of parent-mediated intervention models for children with ASD that aim to capitalize on these associations has involved mostly families of similar backgrounds (Baranek et al., 2015; Roberts & Kaiser, 2011; Rogers et al., 2012; Wetherby et al., 2014). However, many of the same target parent behaviors used in these interventions have had different, or even opposite, associations with later child behaviors in Latino families compared to findings in non-Latino families in the United States (Grau et al., 2015; Halgunseth, Ispa, & Rudy, 2006; Marquis & Baker, 2014; Rodriguez, Davis, Rodriguez, & Bates, 2006), suggesting that targets in parent-mediated interventions designed for non-Latino White families may not always have the same outcomes for Latino families. Of note, these studies have been carried out in typically developing or developmentally disordered populations, yet such research has not been carried out in the Latino ASD population. Conceivably, modifying intervention targets and strategies to align more closely with values and patterns common in Latino families may improve outcomes for Latino children with ASD.

Culturally Sensitive Intervention

Behavioral interventions found effective for one population may not be effective for all populations (Buzhardt et al., 2015; Parra Cardona et al., 2012). Every intervention contains specific cultural values and expectations in its goals and in the strategies it uses to attain

them. When these values and expectations align with those of the family receiving the intervention, positive outcomes are likely, including high levels of participation and response to treatment (Benish, Quintana, & Wampold, 2011; Castro, Barrera, & Holleran Steiker, 2010; Vigil & Hwa-Froelich, 2004). However, if these values and expectations are incongruent with a family's culture, conflicts may arise (Hwa-Froelich & Vigil, 2004; Zayas & Rojas-Flores, 2002), including strain on social relationships within the family (Garcia, Breslau, Hansen, & Miller, 2012), failure to implement recommendations, and discontinuation of services (Long, Kao, Plante, Seifer, & Lobato, 2015).

Sources of mismatch between an intervention and the target population may include the intervention's goals, content, implementation, or service delivery model (Gorman & Baiter, 1997). While language is a major barrier, merely delivering an established intervention in Spanish may not sufficiently improve cultural congruence for Latinos in the United States (Buzhardt et al., 2015; Castro et al., 2010). Deep, foundational adaptations that make the components of intervention congruent with a culture's perceptions, values, and experiences may be necessary (Castro et al., 2010; Magaña, Lopez, & Machalicek, 2015). Unfortunately, the evidence-based interventions that Latino children receive may not be congruent with their cultural values, as Latino children have largely been ignored in ASD intervention research (Lopez, 2014). In fact, Latino families perceive significant needs and barriers in the early intervention services they receive for a variety of developmental disorders, including a lack of information about how to work with their child (Bailey et al., 1999; Iland, Weiner, & Murawski, 2012). Families report that language barriers also impact the extent to which they are able to build relationships with their child's therapists, impacting the family-centeredness of services they receive (Iland et al., 2012; Zetlin, Padron, & Wilson, 1996). Dissatisfaction with early intervention services may be a reflection of cultural conflicts between the specific interventions families receive and their own values and preferences.

The Current Study

To either adapt current evidence-based interventions or design new interventions for Latino populations, we must have input from members of the Latino community (Buzhardt et al., 2015; Zayas & Rojas-Flores, 2002; Zayas & Solari, 1994), including knowledge of perceptions of intervention models and components of evidence-based practices from parents or other family members of children with ASD. The purpose of this mixed-methods study was to describe the intervention experiences of Latino families, to explore intervention models, strategies, and targets that are perceived as more culturally appropriate, feasible, and acceptable for Latino families, and to understand the variability that likely exists among Latino families. The following research questions were addressed:

1. What are the differences in the ways that non-Latino White (NLW) and Latino Spanish-speaking (LSS) parents of children with ASD living in the same geographic area of the United States perceive the quality and family-centeredness of intervention they are currently receiving or have received?
2. How feasible, appropriate, and acceptable do LSS parents' view common therapy models and evidence-based practices used in ASD intervention?

Methods

This study used a parallel mixed methods approach with quantitative and qualitative data collection at roughly the same time. Quantitative and qualitative results were integrated during analysis and interpretation. In the quantitative strand, a total of 55 parents of young children with ASD completed surveys regarding levels of satisfaction with early intervention, including 27 non-Latino White mono-lingual English-speaking (NLW) parents and 28 Latino Spanish-speaking (LSS) parents. In the qualitative strand, 20 LSS caregivers of young children with ASD participated in one of four focus groups to discuss perceptions of intervention experiences and evidence-based practices. Informed consent was obtained from all participants in their language of choice. This study received IRB approval from the university Office of Human Research Ethics.

Participants and Procedure

Participants in this study were recruited through a state chapter of a national ASD advocacy organization via support group meetings, parent workshops, community events, and their membership network. Additional participants were recruited through an ASD research registry managed by a local intervention provider. LSS parents who completed surveys were invited to participate in a focus group as well. All survey participants were entered into a drawing for a \$50 gift card and focus group participants were given \$20 for their time. Childcare and transportation was offered for focus group participants. All participants were living in the same Southeastern state in the United States.

After providing informed consent, parents completed three surveys, described below, either online, in person, over the phone, or through the mail. Among the LSS participants, five chose to complete the surveys in English and the rest completed them in Spanish. All NLW participants completed the surveys in English.

All focus group participants met inclusion criteria previously described for LSS survey participants; however, primary caregivers were invited to attend alone or with one other caregiver who met a portion of inclusion criteria (native language and ethnicity). Fourteen primary caregivers came alone; one was a grandmother and the rest were mothers. Two mothers also brought other caregivers, (a husband or friend). In one case, a child's aunt and grandmother came instead of the child's primary caregiver. In this case, the aunt was also the parent of an older child with autism (11 years), and this family spoke of experiences with both children during the focus group. Table 1 provides a summary of the demographic characteristics of participants. Participants reported that children had received 3.0 total types of therapies on average, with a range of 1 to 4 types. The most common therapy received was speech therapy. Eleven of the 20 focus group participants also completed surveys in the quantitative phase.

Each focus group comprised of 4 to 6 participants and lasted approximately 2 hours. Focus groups were co-facilitated by the first author and a Latina community member. The first author is a non-native but fluent Spanish speaker with experience serving Latino families in the United States as a speech-language pathologist. The community member was a Peruvian mother of an older child with autism who served a leadership role in a local support group.

Focus groups were audio recorded using the Voice Record application on an iPhone and iPad.

Measures

Quantitative Measures—All participants completed a *Background Information Questionnaire* for demographic information including age, gender, country of origin, native language, education, income, age of child, and diagnostic status. Parents were also asked how long their child has been receiving intervention services and in what capacity (type/frequency of services).

The *Family Outcomes Survey-Revised (FOS-R)* (Bailey et al., 2011) is a 41-item measure using a 5-item Likert scale to assess parents' perceived strengths and needs as they relate to the early intervention support they receive. Included are family outcome subscales (e.g. understanding of their child's strengths/needs/abilities, ability to help their child learn) and helpfulness indicator subscales (e.g. how helpful early intervention has been in teaching parents to communicate their child's needs and help their child develop and learn). Scores range from 1–5 with higher scores indicating higher satisfaction. The *FOS-R* has good internal consistency in English (subscales ranging .73–.95 for Cronbach's alpha; Bailey et al., 2011), as well as in Spanish (.62–.94 on subscales in the family outcomes section; Magaña et al., 2015). The *FOS-R* was administered to quantitative participants only, with an overall Cronbach's alpha of .95 for the LSS participants and .94 for the NLW participants.

The *Measure of Processes of Care - 20 (MPOC - 20)* (King, King, & Rosenbaum, 2004) was used to assess how family-centered parents perceive their child's intervention services. The 20-item scale asks parents to rate how much people who work with their child (a) enable partnership, (b) provide general information, (c) provide specific information about their child, (d) coordinate comprehensive care for the child and family, and (e) are respectful and supportive. Scores range from 1–7 with higher ratings indicating higher satisfaction. The original English scale has good internal consistency with coefficients ranging from .83 to .90 (King et al., 2004). The scale was translated into Spanish by the test creators, but has not yet been used empirically to our knowledge. The *MPOC-20* was administered to quantitative participants only, with an overall Cronbach's alpha of .94 for the LSS participants and .93 for the NLW participants.

Qualitative measures—The focus group guide and its English translation are available in the supplemental materials. Questions were developed and presented to each focus group with additional prompts or follow-up questions as necessary. Facilitators elicited participant perspectives on their child's interventions, including their level of involvement therein and their satisfaction with their level of involvement. Participants were also provided with a description and video examples of four basic evidence-based parent-mediated intervention strategies. Prompting, modeling (including video modeling), naturalistic interventions, and discrete trials were chosen for their commonality in use in clinical settings, potential feasibility as parent-mediated interventions, and range of techniques. Descriptions and videos were taken from the AFIRM modules (Sam & AFIRM Team, 2015). These can be found in Table 2. Final questions focused on caregivers' perceptions of basic delivery

models (parent/clinician-mediated, group/individual, etc.). Throughout the focus groups, participants were asked to comment on the perceived appropriateness, feasibility, and acceptability of the various intervention models, strategies, and targets in the context of their own family.

Data Analysis

Quantitative data analysis—Independent means t-tests were used to compare the two groups for average scores among the subscales. As a part of qualitative and quantitative data integration, post hoc analyses were completed as follows: Using patterns identified in the qualitative data, selected individual items were compared between groups using t-tests, and a repeated measures ANOVA was calculated to compare patterns across subscales within groups. Because our sample size was small, we also calculated Cohen's d effect size to estimate the magnitude of group differences between NLW and LLS, defining 0.20 to 0.40 as a small effect, 0.40 to 0.80 as a medium effect, and >0.80 as a large effect (Hoiat & Xu, 2004). Quantitative data was analyzed using R version 3.2.3 (2015).

Qualitative data analysis—Audio files were transcribed by a team of five natively bilingual student research assistants (RAs) with experience in Spanish from a range of Latin American countries. RAs transcribed audio files, translated them to English, then collaboratively checked translations for accuracy either through back-translation or line-by-line review. A thematic analysis approach was employed with an iterative series of transcript reviews. The first phase included 2–3 readings of the translated transcripts for a strong familiarization with the data. An initial list of codes from the first focus group was developed by two of the authors. A process of constant comparison was employed whereby subsequent focus groups were coded using this list and new codes which emerged from new focus group transcripts were added to the list upon discussion with the research team. Each transcript was reviewed at least three times during the coding process, and bi-weekly research meetings were held to resolve discrepancies. While all qualitative analysis was performed on the English translation of the transcripts, an additional RA coded one of the original Spanish transcripts to ensure accuracy of the translation and to validate the codes. Codes were then consolidated and connected to form categories. To validate the data, transcripts and categories were then reviewed and revised with the Latina focus group facilitator before being connected into broader themes and sub-themes. Data analysis was facilitated by the use of ATLAS.ti7 software (Version 7.5.12.; Berlin, 2017) to manage transcripts, codes, and quotes.

Results

Quantitative Results

All participants self-reported having a child with diagnosed or suspected ASD who was receiving or had previously received intervention services. See Table 1 for demographic information on quantitative participants and their children. With the exception of one NLW father, all participants in the quantitative strand were mothers. NLW parents were mono-lingual native English speakers who were born in the United States and self-reported non-Latino ethnicity and White/Caucasian race. LSS parents were natively mono-lingual Spanish

speakers (with a range of English proficiency), and reported Latino or Hispanic ethnicity with any race. All were born outside of the United States. LSS parents had spent an average of 15.2 (range 7–30) years living in the United States. The majority of participants were from Central America, including 16 from Mexico, 2 each from Honduras and El Salvador, and 1 each from the Dominican Republic, Panama, and Guatemala. Four additional participants were from northern South America, including Peru, Venezuela, and Colombia. Reflective of population trends (U.S. Census Bureau, 2013), NLW parents reported significantly higher levels of education and income compared to LSS parents. This difference was expected, and is not considered a limitation. This NLW sample reflects characteristics of those most often participating in ASD research studies, which was the target comparison group. The LSS sample appropriately represents the target cultural group for this study, including Latino ethnicity, Spanish-speaking, and any other cultural characteristics common among more enculturated families living in the US, including factors related to socio-economic status. Given the demographic data collected, the two samples were well representative of the two populations of interest.

Participants' children were between the ages of 1 and 6 years (mean = 4.7 for NLW, 4.4 for LSS), with no significant difference between groups ($p = .42$). On average, NLW parents reported that their children had received a total of 3.2 types of intervention services, compared to 2.8 for LSS families ($p = .13$). Most parents reported receiving speech and occupational therapy, though a range of other services was reported, including but not limited to physical therapy, developmental therapy, and hippo-therapy.

Results from both surveys can be found in Table 3. There was a significant difference in one *FOS-R* subscale: NLW parents rated their child's interventions as less helpful than LSS parents ($p < .05$) in teaching them "how to help their child develop and learn," though a medium effect size ($d = .45$) suggested a similar pattern in the area of "communicating your child's needs." There were no other differences between groups on any other outcomes or indicators (p -values ranged from .1 to .8), though differences with small to medium effect sizes were noted in the subscales of "support systems" ($d = .31$) and "accessing the community" ($d = .45$), with LSS parents reporting lower satisfaction compared to NLW parents. There were no differences between groups on any of the *MPOC-20* subscales (p -values ranged from .1 to .8).

Qualitative Results

Three themes emerged from the data, each comprised of three to four sub-themes. Participants discussed the impact that autism has had on their lives, especially in their roles as caregivers in Latino families. This included how the stigma of autism influences their involvement/relationship/role within their community as well as their therapy choices and priorities. Participants also discussed how autism has impacted their family and social life. A second theme that emerged involved caregivers' used of therapy strategies. Caregivers had to decipher various messages, sometimes conflicting, regarding therapy strategies, which often resulted in caregivers relying on a variety of strategies rather than comprehensive plans. Participants typically judged a strategy's appropriateness based on its effectiveness for their child and were open to a wide range of strategies. Finally, caregivers expressed several

unmet needs from service providers. They unanimously wanted more involvement in their child's therapy and valued open communication with service providers, though language often stood as a barrier. Caregivers also expressed the need for more professionalism among service providers. All quotations are presented in English. The original Spanish quotations can be found within the supplemental materials. See Table 4 for descriptions of themes and subthemes.

Impact of ASD in the Latino Family

Stigma of ASD in the Latino culture: Many participants referenced the strong stigma that ASD has in the Latino community. They shared that there was much ignorance around what developmental disorders were and what caused them in their home countries, and that children with these disorders were typically shunned from society. Many caregivers still faced criticism and judgment from their communities within the US for having caused their child's ASD or not doing the right things to treat it. This criticism, which came mostly from friends or family, but also from professionals, was a great source of stress for caregivers. Yet, within the individual family context, this stigma had differential, sometimes opposing effects on family life, as described below.

ASD makes or breaks the family: Participants felt that an important aspect of their Latino culture was the united family, where extended family members depend on each other for support. In the case of some families, this support was maintained and beneficial to their child with ASD and their immediate family. One mother explained,

The Latino family is very united. I'm from a Latino family, we're very close. We communicate. We always tell each other everything. For example, if a sibling has a problem, everyone helps. In my case, my, all my siblings, on my side, everyone knows my daughter's diagnosis. And everyone understands me, and everyone has supported me, and everyone has helped me. I'm happy with the support I've had from my family.

Many participants wished for a wider group of family members to be formally involved in their child's therapy, such as siblings, aunts/uncles, and grandparents. They felt wider involvement would allow all family members to successfully interact with the child and for the child's therapeutic social environment to remain consistent across frequent interaction partners. However, all of the participants were first generation immigrants and many struggled to overcome challenges without the support of their extended family nearby.

Conversely, some participants considered the close-knit Latino family to be difficult to maneuver in the context of ASD and its stigma. Some close family members denied that any serious disability impacted the child, claiming that the child is just "spoiled." Parents also received advice from family members that they perceived as harmful to their child, such as spanking. Many parents admitted they had not shared their child's diagnosis with family members in an attempt to avoid expected conflicts. One mother shared, "I haven't wanted to tell them... they bring thoughts that aren't going to solve anything. They're going to make the diagnosis a problem. They're not going to help." There were many examples of significant breaks in families that stemmed from the diagnosis. It was very difficult for

parents to navigate these family conflicts, especially in the context of ordinarily expecting and needing so much support from their extended family.

Seeking social support elsewhere: Because of these difficult family relationships, many families sought social support elsewhere. Many went to support groups with other Latino families of children with ASD. During and after each focus group for this project, participants spontaneously exchanged numbers and shared resources among each other, including local support groups and therapies.

Participants were also all interested in the idea of group intervention when asked about formats for parent education and coaching. They felt they could learn from, understand, and support each other. During one exchange, participants became very lively and enthusiastic about the idea:

Participant 2: In a group we can share all of our experiences.

Participant 3: Experiences.

Participant 4: And we learn from different-

Participant 2: So, we learn from the other, “Oh this worked, yes, so I’m going to try.” And besides we are all in this, we help each other out, right...?

Participant 5: We understand.

Participant 2: We understand each other.

Participant 1: We understand each other. We’re in the same situation.

Participant 2: Emotionally, we’re all in the same boat, right? So, not only is this happening to me but also to them. So it’s important.

Therapy priorities influenced by culture: Participants’ cultural values were reflected in the therapy targets they thought were most important. This was typically communication. Most parents prioritized oral speech, and some understood that augmenting communication might support later speech. However, sign language was sometimes seen as only appropriate for deaf children, not those with other communication needs. Communication was very important to families for safety reasons. They were afraid without speech, their children would fail to get their needs met around strangers or that they, as parents, would fail to find out about safety concerns impacting the child, such as bullying. Other important goals for families were the child’s self-regulation and behavior.

Caregivers’ priorities for therapy targets balanced between the skills they thought their child needed in order to be successful in the future and how they perceived their family, friends, and society would view their child in the future. This dichotomy was exemplified when one mother shared that she was helping to teach her son to point, a behavior considered rude in her culture: *“I’m practical. If I have to leave my culture aside, I will leave it, my son is first... My son needs to learn that, so I’m teaching my son to point... My children come first before my culture.”* This sentiment was largely echoed by the other participants in that focus group.

Mix and Match Therapy Strategies

Variety of messages: Caregivers expressed receiving various messages over time regarding therapy choices across therapists, family members, friends, other parents, teachers, or even online. Parents worked hard to use the strategies that they perceived to work best for their children. These were typically visual prompts, structured schedules, choices, reward plans, or enhanced sensory input. Yet this inevitably meant they were not using any comprehensive plans but rather mixed and matched therapy strategies for the moment or situation. As a result, they often felt overwhelmed and admitted that they sometimes lost patience. One mother expressed difficulty working with her child with co-morbid hyperactivity, *“We have to work to tire him, but I think the ones tired out just end up being us. So then we try to give him tasks but it’s hard, honestly.”*

Strategies’ success worth the effort: Typically, participants’ overall perception of a particular strategy was foundationally linked to their perception of its effectiveness rather than its feasibility or appropriateness. Many participants commented that several strategies were difficult to learn at first, but that the effort was worthwhile when the strategy was effective. One mother expressed difficulty in carrying out a recommended strategy, stating, *“It breaks my heart so much to do that, but it’s that he has to be independent.”* In general, participants described the struggle in learning and using new or challenging strategies, but shared that the sacrifice was worth their child’s progress and future independence. Despite this rationalization, there were multiple examples of caregivers discontinuing strategies because of their difficulty in maintaining within their family lifestyle, e.g. strict visual schedules or consistent daily routines.

Open to a variety of strategies: When presented with specific examples of therapy strategies, caregivers were open to a wide variety of strategies. Most strategies were positively viewed, and caregivers hesitated to choose a preferred option, stating that they needed multiple strategies throughout the day.

Among the presented strategies (see Table 2), prompting was especially appreciated. Several participants viewed physical prompting as positive because it incorporated physical connection with the child. One mother shared, *“It’s physical contact with me, or with the dad or the person that is helping him. And I find it a good way of boosting his independence... he will feel more able to do things himself because he will have a framework [of] what it is he has to do.”* However, participants typically felt physical prompts were only appropriate for very young children. Many caregivers frequently used verbal or visual prompting strategies at home. Modeling was considered an easy and useful strategy depending on the child’s skills. Video modeling was often unfamiliar to participants, but thought to be potentially beneficial given their children’s interest in technology and ability to learn visually. Participants felt using technological devices may also be feasible, if safety with technology could be controlled. Participants were conflicted about the various facets of naturalistic interventions. They felt that responsive behaviors, like following the child’s lead, were natural and easy to implement, while strategies like sabotage or wait time were difficult to implement as parents typically avoided frustrating children, even temporarily. Most

participants were open to discrete trials as they often used longer term positive or negative reinforcement strategies at home.

Unmet Needs from Service Providers—Participants were overall very grateful for the services they received from providers. However, when therapy experiences were discussed in depth, they expressed many unmet needs. These were viewed as barriers that impeded their child's ability to reach their full potential.

Involvement in therapy: Many parents felt unsure of how to interact with their children at home and often blamed this on lack of support from providers. According to one mother, *"The [providers] have not communicated with me so I don't know what to do or how to work with this."* Participants unanimously agreed that they wanted more involvement in their child's therapies and support from therapists around how to work with their child at home.

Many parents noted a drastic difference in their involvement and the level of family support they received across service providers. When therapies were provided individually in private clinics or in the home, parents commented that they were able to either observe or actively participate in therapy. Parents highly appreciated this opportunity as they felt it allowed them to learn strategies to use at home. One mother described her experience with a private therapist, saying, *"Because when he gets therapies I'm always there with him, observing. I see how they work, I do it at home too. That has helped me out a lot because I become more involved."* However, when therapies were carried out in the school environment, parents were less involved. Many did not communicate frequently with their child's therapists. According to one mother, *"The school ones, I don't have much contact with them."* Parents shared that school personnel discouraged them from observing their child during the school day to avoid disrupting the class structure. Many participants agreed that their children were more likely to behave better and learn more when parents were not present, but lamented that this meant parents were unable to learn strategies to use at home. One mother shared:

It's something like a balance. It's very good to have therapies away from the parents because in my case the children participate more, they have a better formed structure, because they know they have to do it. But at the same time the disadvantage is that we stay out so then we don't learn.

Parents felt they were vital members of the intervention team and emphatically expressed that they wanted therapists to not only work with the child but to work with the family as well. One mother argued, *"What we want is for them to give classes to us. Because the classes, they only give them to the kids, we want a base so that we can learn too."* Another mother shared emotionally, *"Can I tell you the truth? It's not pointless for someone to teach me how to work with my son."* Parents felt that their increased involvement in their child's therapies would allow them to work with their children at home and thus maximize the impact that intervention has. One mother reasoned, *"Because we all have to be involved, for the good of the child. Because even though the therapist works with the child, she also has to teach us, teach me, how to work with him. I think it's for the good of the child."* All participants whose children were receiving preschool or school-age services agreed that they wanted more support from their school therapists. Participants were open to various models of family support, including class or therapy observations, hands-on practice with therapists

or educators, or group workshops for families. One mother of a younger child became concerned about the possible loss of family support once they transitioned from infant-toddler services to preschool services and planned to volunteer in her child's classroom to stay involved. She commented:

I want, to observe how they're going to give my child therapy. Because I don't only want them to come and give me a paper and say "we're reaching the goals and we're working on this." I want to see how they work and I want to see that it is working ... that he is progressing. I want to see it. I want to see how they follow their structure, how they work with the kids, I want to know everything, I want to see everything... I want him to take advantage of a hundred percent of the therapy. I don't only want him to take advantage of twenty-five percent.

Several parents shared that in the absence of sufficient support from or involvement with therapists, they had turned to the internet to look for ways to work with their child, while others sought additional private therapy. One mother reasoned, *"If I could have more participation in school therapies, quite possibly I would not have private therapy."*

Open communication: Participants valued open communication with service providers. One mother described, *"The communication is the first key to open up the door. If there isn't communication between the parents and the therapist, there won't be anything."* Many mentioned that school providers gave them worksheets or written communication about tips for working with their child at home. Similarly, many commented that these topics were discussed in IEP meetings. However, this appeared to be insufficient for participants to then successfully carry out recommendations at home. According to one mother,

"[At school,] I wish I could see, be there, participate, learn. Because it's very good the information that they send me and it's very well explained and everything for me to work with him. But I would still like to see. It's not the same learning from a guide or a paper as seeing a professional doing the things."

Participants also felt that, as family members, they had unique knowledge about their child, such as how the child was responding to new therapy strategies or environments or new skills the child was learning at home. Open communication between family members and providers would allow families to share such imperative information with the intervention team so that the child could receive the greatest benefit.

The language barrier was one of the main impediments to open communication. Many insisted that Spanish skills were imperative to building a relationship where this communication could flow smoothly. One mother explained, *"The moms that don't speak English can't help their kids because they don't know how. Because as much as they explain to them, well, [it's] Chinese. I haven't been able to understand."* Alternatively, one mother shared positive experiences when two of her child's providers spoke Spanish:

In my case the developmental play therapy, a bilingual Hispanic young woman, and the speech therapist, a bilingual American. So I could communicate well with both. I had a good experience with them both because the communication was open.

Same for my husband who doesn't speak a lot of English. So then my husband could also talk to them.

Participants experienced difficulties working with provider agencies without Spanish-speaking staff or interpreters. They perceived a serious shortage of Spanish-speaking service providers and often endured long wait times to work with one. They emphatically argued that in order for service providers to effectively serve Latino families, they must speak Spanish. As one mother described, *"I really think they have to choose not only capable people, and above all most important, they have to be bilingual... So they can work in the cases that require it. In Hispanic homes or Latino homes."* However, for the caregivers with higher English proficiency, language was not perceived as a barrier.

Professionalism: Unfortunately, many caregivers expressed a dissatisfaction with the professionalism exhibited by some service providers, such as providers who would use their cell phones or fall asleep during therapy sessions. This required many parents to take a more leadership role in therapy than they would have liked. One mother shared, *"I feel like I do more than the therapist in the therapy session."* Another mother commented that her child's therapists *"don't put in a hundred percent."* Other participants commented that therapists do not work on the agreed upon goals. Another mother noted, *"If you aren't demanding and demanding, some agencies send you whatever person that was sitting there. Counting the minutes as they pass and they don't do anything. So that's what's happening with my daughter."*

Most parents commented that their unsatisfactory service was due to either a lack of preparation or passion for their work. When asked what would qualify a service provider for working with families, one mother shared, *"I think that love, that they should love their job and our kids because if they love our kids they will give it their all... They will put all their effort in working towards the goals, they will read them."* Participants recognized that many teachers and therapists are working hard, but many expressed that they still needed more support and professionalism.

Integration of Qualitative and Quantitative Data

Two of the subthemes, autism making or breaking the family and parents seeking social support elsewhere, as well as one theme, unmet needs from service providers, were addressed to some extent within the surveys. Post-hoc quantitative analyses were performed to determine whether findings were reflected similarly in both forms of data. Four items on the FOS-R related to social support. LSS parents rated two of these items significantly lower than NLW parents (See Table 5; $t = 2.07, p < .05$; $t = 2.75, p < .001$ respectively). The two remaining items were also rated lower, with effect sizes of .41 and .23, though differences were not significant ($p = .13, .38$ respectively). Two additional items on the FOS-R were chosen for comparison as they related to professionals developing relationships with family members and respecting their choices. Significant differences were found, such that NLW parents were less satisfied than LSS parents (See Table 5; $p < .01$; $p < .001$ respectively). As the entire MPOC-20 is related to the family-centeredness of care, a repeated measures ANOVA was performed for both groups separately to analyze the pattern of results within each group. Seemingly in contrast to the qualitative findings, the LSS parents reported

significantly more satisfaction in the area of respectful and supportive care compared to providing general information ($p > .001$), a pattern marginally significant in the NLW group ($p = .06$).

Discussion

In this study of NLW and LSS caregivers of young children with ASD, we sought to understand differences in perceptions of early interventions between groups as well as to identify various factors involved in Latino caregivers' perceptions of therapy strategies, service providers, intervention targets, and models of intervention. The Latino community has been widely overlooked in autism research despite the sizable Latino population in the United States (Lopez, 2014). This study presents several findings that are empirically and clinically significant for Latino families receiving intervention for ASD.

The quantitative comparisons revealed very few differences between NLW and LSS caregivers with respect to overall perceptions of the helpfulness and family-centeredness of early intervention. The only significant difference in subscales showed that NLW families perceived early intervention as less helpful than LSS parents in teaching parents how to help their children develop and learn, though a similar trend was observed in teaching parents how to communicate their child's needs. This finding contradicts past studies in which Latino parents of children with developmental delays report that they need more information on how to work with their children (Bailey et al., 1999; Iland et al., 2012). However, this difference may not represent a lack of need in Latino families, but rather need in both groups, with greater perceived need in the NLW caregivers. Alternatively, the two groups may be responding to survey items using different mental scales. Even with identical Likert terms, differences of survey responses across cultural groups have been documented (Harzing, 2006). There is some evidence that LSS individuals may be more likely to report higher satisfaction on surveys than in qualitative methods (Aday, Chiu, & Andersen, 1980; Saint-Germain, Bassford, & Montano, 1993), and that NLW individuals are less likely to respond positively to survey items than Latino individuals (Johnson, Shavitt, & Holbrook, 2011). Consequently, a lack of differences between groups on other subscales in this study may not indicate a lack of perceived areas of need or dissatisfaction among LSS families.

Medium effect sizes also suggested that LSS parents may have perceived less access to the community as compared to NLW white parents. This finding is likely related to the difference in income and education levels between the two groups, and possibly language barriers faced by LSS families. Reduced access to services for autism among Latino families has been documented in the literature (Lobar, 2014).

In order to complement the quantitative data in this study, focus groups were used to elicit additional information on LSS families' perceptions of specific evidence based practices and experiences with interventions. In this study, the additional qualitative data provided further supportive and sometimes contrasting information when compared to survey data. Other studies with Latino participants have found similar patterns of asynchronous or contrasting findings when comparing qualitative and quantitative data (Aday et al., 1980; Bender, Harbour, Thorp, & Morris, 2001; Saint-Germain et al., 1993). These replicated findings

represent significant clinical and empirical implications that qualitative data appears to be imperative to fully answer clinical or research questions within this population.

Cultural Influence

Focus group data revealed several findings around the theme of the influence of ASD on Latino families. A considerable amount of literature has identified close relationships within a large extended family as a common feature in Latino communities (Harwood, Leyendecker, Carlson, Asencio, & Miller, 2002), which was referenced within the focus groups. Several participants in this study spoke of the benefits of this social network as they faced parenting challenges. They felt involvement of extended family members in therapy would be beneficial, although many did not have family nearby. Conversely, many participants discussed the drawbacks from having a close-knit family. The stigma around ASD negatively affected the way they were able to interact with family members and participate in their broader communities. The stigma of ASD in the Latino community, as well as of developmental disabilities in general, has been well documented in the literature (Blanche, Diaz, Barretto, & Cermak, 2015; Lobar, 2014; Zuckerman et al., 2014). Not surprisingly, Latino families of children with ASD or other developmental disorders have also reported family conflicts and social isolation (Bailey et al., 1999; Blanche et al., 2015; Lobar, 2014). This pattern was reflected within the quantitative data in this study through significant differences between NLW and LSS parents on two of four survey items related to social support, with LSS parents reporting less social support. In the absence of beneficial support networks, many LSS caregivers turned to support groups with other Latino families of children with ASD, a pattern that has also been documented in the literature (Lobar, 2014). In order to best serve these families, providers could help connect families with local Spanish-speaking support groups, or provide family support with extended family members in a group model. Following collaboration with community members, two parent-mediated ASD interventions designed specifically for Latino families have incorporated the value of family relationships, *familismo*, in their interventions (Buzhardt et al., 2015; Magaña et al., 2015).

While the theme related to participants' views about Latino culture was discussed in each focus group, it was usually discussed less directly and with less frequency than the other topics. This may indicate that participants are relatively unaware of how their culture impacts their experiences and perceptions. This finding is clinically significant as families may be less likely to bring up culturally-related concerns with their providers from other backgrounds if they assume these concerns are universal rather than culture-specific. Zayas and Solari (1994) recommend engaging Latino caregivers in conversations about their parenting values so that these can be held central to the intervention plan. Service providers may need to find ways to ask questions that will reveal these values clearly.

Perceptions of Interventions

Participants used a wide range of strategies with their children, though they mostly pieced together parts of various approaches, specific to the situation or moment, without using any consistent therapy plans at home. They all stressed the need for more support from providers to learn how to work with their children at home. Previous research has shown that Latino

families of children with disabilities feel they are not provided with enough information about how to help their child at home (Bailey et al., 1999; Iland et al., 2012).

Participants typically viewed all presented evidence-based practices positively, though some practices were viewed differently. Prompting was viewed especially highly, which may reflect the common finding that Latino parents often use scaffolding as a parenting strategy (Harwood et al., 2002; Marquis & Baker, 2014; Windham et al., 2012). The specific preference for physical prompting for young children is also reflected in the literature, where findings indicate that frequent physical support for young children is common and beneficial in Latino families from a variety of backgrounds (Carlson & Harwood, 2003; Fischer, Harvey, & Driscoll, 2009; Halgunseth et al., 2006). Modeling was perceived positively, with the addition of video modeling seen as an unfamiliar but potentially beneficial and feasible strategy. Participants perceived discrete trials as a strategy frequently used by therapists but were open to using the strategy at home. Most participants were already using longer term rewards or consequences with their children at home.

The various components of naturalistic interventions were perceived differently by participants. Responsiveness and following the child's lead was perceived as helpful, important, and somewhat natural to implement, which is not supported by prior findings suggesting that Latino families may respond poorly to child-directed strategies (Carlson & Harwood, 2003). Alternatively, wait-time, environmental arrangement, and sabotage were viewed as more difficult by many participants. They felt these strategies were likely to frustrate or upset their child, which they typically tried to avoid. This may be a reflection of a more co-dependent parenting practice identified in the literature that is common among Latino families, where parents care for children longer and value personal relationships and closeness over independence (Zayas & Solari, 1994). Alternatively, parents could be concerned that frustrating children will increase problem behaviors, which is frequently cited as a major concern of Latino parents (Bailey et al., 1999; Chavira, López, Blacher, & Shapiro, 2000; Zuckerman et al., 2014).

It should be noted, however, that some parents were willing to set aside these values if they perceived their child would gain long-term benefits. Though participants were asked directly and indirectly about how well certain therapeutic strategies would fit with their culture, almost all were more concerned about the strategy's perceived effectiveness than their willingness to carry it out or its feasibility in their home. Many families seemed to take an "ends justify the means" standpoint regarding their choices for both therapy strategies and child behaviors. Even if strategies were difficult to learn or child behaviors were less culturally appropriate, these concerns may not outweigh their child's potential developmental gains. This contrasts with literature that suggests interventions that conflict with a family's cultural values are more likely to be less effective or even rejected by the family (Zayas & Solari, 1994). Importantly, though, some caregivers in this study did admit to discontinuing strategies that were too hard to maintain.

Because of participants' positive opinions of and experiences with prompting, modeling, responsiveness, and positive/negative reinforcement, these may be good choices of strategies to offer to Latino caregivers. They may benefit from direct support with these strategies so

that they are able to maximize their effectiveness. Service providers may consider avoiding environmental arrangement strategies when coaching caregivers, or alternatively complement these strategies with additional scaffolding or behavior management strategies. Many caregivers in this study were willing to attempt difficult strategies if they felt the outcome would be worth the effort, thus providers may offer a clear rationale for using strategies that may be non-preferred. For example, Buzhardt et al. (2015) included extra parent-education sessions to relate intervention goals to Latino values as well as to provide extra rationale for intervention targets as a way to make their intervention more culturally appropriate for Latino families. While participants in this study shared their opinions about specific strategies, several declined to choose only one preferred strategy. Many expressed the need for multiple strategies to use, according to the child's mood or temperament. Service providers should consider helping caregivers learn a variety of strategies to use at home.

Additional Needs

Families of children receiving services at home or in a clinic environment were most often receiving individualized instruction while the caregivers were present. This model facilitated caregiver involvement and support. However, caregivers described the unfortunate absence of this level of involvement in the preschool or school-based model. This finding appeared to contrast with previous research suggesting Mexican families may prefer a less direct role in therapy involvement (Rodriguez & Olswang, 2003). Yet most research eliciting perceived needs from Latino families have identified the need for more information about how to work with their children (Bailey et al., 1999; Iland et al., 2012). Providers may need to carefully and fully elicit preferences from Latino families to determine their individual expectations for involvement. In any case, service providers may need to find alternative models to better support families that will fit within the school model. Some research has found positive outcomes by utilizing teacher work days and time after school for workshops (Ingersoll, Wainer, Berger, Pickard, & Bonter, 2016). Two mothers in this study spoke highly of teachers hosting parent workshops in the classroom during the school day.

When discussing services, caregivers valued open communication with service providers, including close relationships, frequent communication, and parental support. Bender et al. (2001) discussed the importance of small-talk with Latino families in the context of medical visits in order to establish trust and facilitate open communication. Many participants also discussed language barriers between themselves and their child's providers and emphatically argued for the need for bilingual providers. Language barriers have also been raised as difficulties in other studies of Latino families (Blanche et al., 2015). To meet this need for relationship building, several behavioral interventions adapted for Latino families have incorporated specific relationship building strategies, including using bilingual and culturally Latino staff to carry out intervention sessions, or building time for small talk into sessions (Borrego, Anhalt, Terao, Vargas, & Urquiza, 2006; Buzhardt et al., 2015; Magaña et al., 2015; Parra Cardona et al., 2012). The lack of racial, ethnic, and linguistic diversity in service providers is an issue facing many clinical fields. Continued or strengthened efforts to recruit bilingual students to allied health and education fields is likely to improve intervention experiences for families. Especially worrisome are the experiences of multiple

LSS caregivers with unprofessional service providers. This finding raises concerns about the providers that agencies are employing, and whether less capable or motivated providers are at times assigned to LSS families whose limited English fluency may prohibit formal complaint.

Limitations

Sample size was limited for this study. Recruitment proved difficult for the LSS group, as has been documented in other studies (Haack, Gerdes, & Lawton, 2014; Rodriguez et al., 2006). To facilitate recruitment, many participants were contacted from local support groups or parent networks for Spanish-speaking families of children with autism, which may have inflated the finding related to caregivers seeking social support outside the family. This explanation is certainly plausible considering the stigma of ASD within the Latino community, and the possibility that many caregivers may have socially isolated themselves in an attempt to keep their child's condition from other community members. Participants not recruited from support groups or advocacy networks were most often recruited from a state-wide service provider associated with the university that conducted the research. These participants may have had unique experiences that are not shared by other families. Of note, this provider was not frequently discussed in the focus groups and primarily provides diagnostic rather than intervention services to families.

It is important to note the heterogeneity within LSS individuals, who come from multiple continents, countries, and a wide range of cultural backgrounds. Most focus group participants were originally from Mexico. While some participants were from other countries, it is possible that the views expressed in this study differ from Latino families of other nationalities, regions, or cultural backgrounds. Additionally, we recruited male caregivers, yet only one participated in the focus groups. Although Blanche et al. (2015) found that Latina mothers tend to take primary caregiving roles, especially among families of children with ASD, Harwood et al. (2002) suggests that there may be as much heterogeneity in the roles of fathers in Latino cultures as in other cultures, and a larger male sample may have identified differing perspectives.

The sample was drawn from a single state in the Southeastern US. Thus, the perspectives of parents in this state may differ from those in other states with different demographics, different early intervention service resources, and different policies and practices that could impact families' services.

Due to resource constraints, qualitative data was not collected from NLW participants. While the focus of this study was to find intervention models, targets, and strategies perceived positively among LSS participants specifically, it is possible that NLW families share similar perspectives.

Also of note is the fact that none of the authors on this paper are of Latin American descent or native Spanish speakers. Given the nature of empirical research, whether quantitative or qualitative, conclusions drawn from analysis will be influenced by the researchers themselves, including their perspectives and experiences (Moustakas, 1994). Members of the Latino community were involved during the majority of the research process, including

choosing of sampling techniques, translation of research materials, quantitative and qualitative data collection, and qualitative data analysis. However, the research team leadership did not include members of the Latino community, which may have strengthened the validity of the conclusions presented here.

Finally, survey instruments used here were translated by test creators and not re-tested for reliability and validity on a large sample of LSS individuals, as is suggested when using an instrument with a new population (Beaton, Bombardier, Guillemin, & Ferraz, 2000). The *FOS-R* had been used previously in the literature with an LSS sample (Magaña et al., 2015), however the *MPOC-20* had not. Although high internal consistency was achieved within this sample, it is possible that these were not reliable or valid instruments for use with our LSS participants.

Future Directions

Therapy strategies identified here should be an area of further research. Interventions could be developed or modified to capitalize on the areas of strength, comfort, and perceived importance for Latino families. Empirical studies of these interventions could determine if providers can help Latino caregivers to become more effective in familiar strategies or learn new strategies that benefit their children. Additionally, alternative and innovative ways to increase family involvement and communication within school models could provide Latino families with needed supports. Research is also needed in the area of recruitment and retention of bilingual post-secondary students to education and allied health fields. Finally, although the caregivers in this study all had children with ASD or suspected ASD, many of the strategies presented and topics discussed may relate to children with other developmental disabilities. Future research could determine if Latino caregivers of children with developmental disabilities other than ASD have similar or differing perspectives.

Ethical Standards

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. The authors declare that they have no conflicts of interest.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

This project was funded by the Carolina Center for Public Service through a Community Engagement Fellowship. The Autism Research Registry, which assisted in recruitment, is supported by a grant from The National Institute for Child Health and Human Development (P30-HD003110) to the University of North Carolina at Chapel Hill. We would like to thank each family who participated in this study as well as the research assistants for their hard and tedious work. We would also like to thank our co-facilitator, Diana Wilkenson for her work and dedication to this project. This project was presented in a poster at the International Meeting for Autism Research, 2017.

References

- Aday L, Chiu G, Andersen R. Methodological issues in health care surveys of the Spanish heritage population. *American Journal of Public Health*. 1980; 70:367–374. [PubMed: 7361954]
- ATLAS.ti7. Version 7.5.12. [Computer software]. Berlin: Scientific Software Development; 2017.
- Bailey D, Raspa M, Olmsted M, Novak S, Sam A, Humphreys B, Nelson R, Guillen C. Development and psychometric validation of the Family Outcomes Survey-Revised. *Journal of Early Intervention*. 2011; 33(6):6–23.
- Bailey D, Skinner D, Correa V, Arcia E, Reyes-Blanes M, Rodriguez P, Skinner M. Needs and supports reported by Latino families of young children with developmental disabilities. *American Journal on Mental Retardation*. 1999; 104:437–451. [PubMed: 10541414]
- Baranek G, Watson L, Turner-Brown L, Field S, Crais E, Wakeford L, Reznick J. Preliminary efficacy of adapted responsive teaching for infants at risk of autism spectrum disorder in a community sample. *Autism Research and Treatment*. 2015; 2015:1–16.
- Beaton D, Bombardier C, Guillemin F, Ferraz M. Guidelines for the process of cross-cultural adaptation of self-report measures. *Spine*. 2000; 25:3186–3191. [PubMed: 11124735]
- Bender DE, Harbour C, Thorp J, Morris P. Tell Me What you Mean by “Si”: Perceptions of Quality of Prenatal Care among Immigrant Latina Women. *Qualitative Health Research*. 2001; 11(6):780–794. [PubMed: 11710077]
- Benish S, Quintana S, Wampold B. Culturally adapted psychotherapy and the legitimacy of myth: A direct-comparison meta-analysis. *Journal of Counseling Psychology*. 2011; 58(3):279–289. [PubMed: 21604860]
- Blanche E, Diaz J, Barretto T, Cermak S. Caregiving experiences of Latino families with children with autism spectrum disorder. *The American Journal of Occupational Therapy*. 2015; 69(5):1–11.
- Borrego J, Anhalt K, Terao S, Vargas E, Urquiza A. Parent-child interaction therapy with a Spanish-speaking family. *Cognitive and Behavioral Practice*. 2006; 13:121–133.
- Buzhardt J, Rusinko L, Heitzman-Powell L, Trevino-Maack S, McGrath A. Exploratory evaluation and initial adaptation of a parent training program for Hispanic families of children with autism. *Family Process*. 2015; 55(1):1–16.
- Carlson V, Harwood R. Attachment, culture and the caregiving system: The cultural patterning of everyday experiences among Anglo and Puerto Rican mother-infant pairs. *Infant Mental Health Journal*. 2003; 24(1):53–73.
- Castro F, Barrera M, Holleran Steiker L. Issues and challenges in the design of culturally adapted evidence-based interventions. *Annual Review of Clinical Psychology*. 2010; 6:213–239.
- Chavira V, López S, Blacher J, Shapiro J. Latina mothers’ attributions, emotions, and reactions to the problem behaviors of their children with developmental disabilities. *Journal of Child Psychology and Psychiatry*. 2000; 41(2):245–252. [PubMed: 10750550]
- Elder J, Valcante G, Won D, Zylis R. Effects of in-home training for culturally diverse fathers of children with autism. *Issues in Mental Health Nursing*. 2003; 24(3):273–295. [PubMed: 12623686]
- Fischer C, Harvey E, Driscoll P. Parent-centered parenting values among Latino immigrant mothers. *Journal of Family Studies*. 2009; 15:296–308.
- Fontil L, Petrakos H. Transition to school: The experiences of Canadian and immigrant families of children with autism spectrum disorders. *Psychology in the Schools*. 2015; 52:773–788.
- Garcia E, Breslau J, Hansen R, Miller E. Unintended consequences: An ethnographic narrative case series exploring language recommendations for bilingual families of children with autistic spectrum disorders. *Journal of Medical Speech-Language Pathology*. 2012; 20(2):10–16.
- Gorman J, Baiter L. Culturally sensitive parent education: A critical review of quantitative research. *Review of Education Research*. 1997; 67(3):339–369.
- Grau J, Duran P, Castellanos P, Smith E, Silberman S, Wood L. Developmental outcomes of toddlers of young Latina mothers: Cultural, family, and parenting factors. *Infant Behavior & Development*. 2015; 41:113–126. [PubMed: 26454205]

- Haack LM, Gerdes AC, Lawton KE. Conducting research with Latino families: Examination of strategies to improve recruitment, retention, and satisfaction with an at-risk and underserved population. *Journal of Child and Family Studies*. 2014; 23(2):410–421.
- Halgunseth L, Ispa J, Rudy D. Parental control in Latino families: An integrated review of the literature. *Child Development*. 2006; 77:1282–1297. [PubMed: 16999798]
- Harwood, R., Leyendecker, B., Carlson, V., Asencio, M., Miller, A. Parenting among Latino families in the U.S. In: Bornstein, M., editor. *Handbook of Parenting: Vol. 4: Social conditions and applied parenting*. 2. Mahwah, NJ: Lawrence Erlbaum Associates Publishers; 2002. p. 21-46.
- Harzing A-W. Response Styles in Cross-national Survey Research. *International Journal of Cross Cultural Management*. 2006; 6(2):243–266.
- Hojat M, Xu G. A visitor's guide to effect sizes: statistical significance versus practical (clinical) importance of research findings. *Advances in Health Sciences Education: Theory and Practice*. 2004; 9(3):241–249. [PubMed: 15316274]
- Hwa-Froelich D, Vigil D. Three aspects of cultural influence on communication: A literature review. *Communication Disorders Quarterly*. 2004; 25(3):107–118.
- Iland E, Weiner I, Murawski W. Obstacles faced by Latina mothers of children with autism. *Californian Journal of Health Promotion*. 2012; 10:25–36.
- Ingersoll B, Wainer A, Berger N, Pickard K, Bonter N. Comparison of a self-directed and therapist-assisted telehealth parent-mediated intervention for children with ASD: A pilot RCT. *Journal of Autism and Developmental Disorders*. 2016; 46:2275–2284. [PubMed: 26922192]
- Johnson, T., Shavitt, S., Holbrook, A. Survey response styles across cultures. In: Matsumoto, D., van de Vijver, F., editors. *Cross-Cultural Research Methods in Psychology*. Cambridge: Cambridge University Press; 2011. p. 130-175.
- King S, King G, Rosenbaum P. Evaluating health service delivery to children with chronic conditions and their families: development of a refined measure of processes of care. *Child Health Care*. 2004; 33:35–57.
- Koegel, R., Schreibman, L., Britten, K., Burke, J., O'Neill, R. A comparison of parent training to direct child treatment. In: Koegel, R., Rincover, A., Egel, A., editors. *Educating and Understanding Autistic Children*. Houston: College Hill Press; 1982. p. 260-279.
- Lobar S. Family adjustment across cultural groups in autistic spectrum disorders. *Advances in Nursing Science*. 2014; 37(2):174–186. [PubMed: 24786205]
- Long K, Kao B, Plante W, Seifer R, Lobato D. Cultural and child-related predictors of distress among Latina caregivers of children With intellectual disabilities. *American Journal on Intellectual and Developmental Disabilities*. 2015; 120(2):145–165. [PubMed: 25715183]
- Lopez K. Sociocultural perspectives of Latino children with autism spectrum disorder. *Best Practices in Mental Health*. 2014; 10(2):15–31.
- Magaña S, Lopez K, Machalicek W. Parents Taking Action: A psycho-educational intervention for Latino parents of children with autism spectrum disorder. *Family Process*. 2015:1–16. [PubMed: 25783619]
- Mahoney G, Perales F. Using relationship-focused intervention to enhance the social-emotional functioning of young children with autism spectrum disorders. *Topics in Early Childhood Special Education*. 2003; 23(2):77–89.
- Marquis W, Baker B. An examination of Anglo and Latino parenting practices: Relation to behavior problems in children with or without developmental delay. *Research in Developmental Disabilities*. 2014; 35(2):383–392. [PubMed: 24334227]
- McConachie H, Diggle T. Parent implemented early intervention for young children with autism spectrum disorder: a systematic review. *Journal of Evaluation in Clinical Practice*. 2007; 13(1): 120–129. [PubMed: 17286734]
- Moustakas, C. *Phenomenological Research Methods*. Thousand Oaks: Sage Publications, Inc; 1994. Phenomenology and human science inquiry; p. 43-67.
- Parra Cardona J, Domenech-Rodriguez M, Forgatch M, Sullivan C, Bybee D, Holtrop K, Bernal G. Culturally adapting an evidence-based parenting intervention for Latino immigrants: The need to integrate fidelity and cultural relevance. *Family Process*. 2012; 51(1):56–72. [PubMed: 22428711]

- Patterson S, Smith V, Mirenda P. A systematic review of training programs for parents of children with autism spectrum disorders: Single subject contributions. *Autism*. 2011; 16:498–522.
- R Core Team. R: A language and environment for statistical computing. R Foundation for Statistical Computing; Vienna, Austria: 2015. URL <https://www.R-project.org/>
- Roberts M, Kaiser A. The effectiveness of parent-implemented language interventions: A meta-analysis. *American Journal of Speech-Language Pathology*. 2011; 20:180–199. [PubMed: 21478280]
- Rodriguez B, Olswang L. Mexican-American and Anglo-American mothers' beliefs and values about child rearing, education, and language impairment. *American Journal of Speech-Language Pathology*. 2003; 12:452–462. [PubMed: 14658997]
- Rodriguez M, Davis M, Rodriguez J, Bates S. Observed parenting practices of first-generation Latino families. *Journal of Community Psychology*. 2006; 34(2):133–148.
- Rogers S, Estes A, Lord C, Vismara L, Winter J, Fitzpatrick A, Dawson G. Effects of a brief early start Denver model (ESDM)-based parent intervention on toddlers at risk for autism spectrum disorders: A randomized controlled trial. *Journal of the American Academy of Child and Adolescent Psychiatry*. 2012; 51:1052–1065. [PubMed: 23021480]
- Rogers, S., Vismara, L. Interventions for infants and toddlers at risk for autism spectrum disorder. In: Volkmar, F., Rogers, S., Paul, R., Pelphrey, K., editors. *Handbook of Autism and Pervasive Developmental Disorders*. 4. John Wiley & Sons, Inc; 2014. p. 739–765.
- Saint-Germain M, Bassford T, Montano G. Surveys and focus groups in health research with older Hispanic women. *Qualitative Health Research*. 1993; 3:341–367.
- Sam, A. AFIRM Team. AFIRM Modules. Chapel Hill, NC: National Professional Development Center on Autism Spectrum Disorder, FPG Child Development Center, University of North Carolina; 2015. Retrieved from <http://afirm.fpg.unc.edu>
- Siller M, Sigman M. Modeling longitudinal change in the language abilities of children with autism: Parent behaviors and child characteristics as predictors of change. *Developmental Psychology*. 2008; 44:1691–1704. [PubMed: 18999331]
- Tamis-LeMonda C, Bornstein M, Baumwell L. Maternal responsiveness and children's achievement of language milestones. *Child Development*. 2001; 72:748–767. [PubMed: 11405580]
- Technical Assistance and Dissemination Network. Historical state-level IDEA data files. 2011. Retrieved on 2/8/16 from <http://tadnet.public.tadnet.org/pages/712>
- Vigil D, Hwa-Froelich D. Interaction styles in minority caregivers: Implications for intervention. *Communication Disorders Quarterly*. 2004; 25(3):119–126.
- U.S. Census Bureau. Current Population Survey, Annual Social and Economic Supplement. 2013
- Wetherby A, Guthrie W, Woods J, Schatschneider C, Holland R, Morgan L, Lord C. Parent-implemented social intervention for toddlers with autism: An RCT. *Pediatrics*. 2014; 134:1084–1093. [PubMed: 25367544]
- Windham GC, Smith KS, Rosen N, Anderson MC, Grether JK, Coolman RB, Bingham A. Observed parenting practices of first-generation Latino families. *Journal of Autism and Developmental Disorders*. 2012; 43(2):1–16.
- Woods J, Wetherby A. Early identification of and intervention for infants and toddlers who are at risk for autism spectrum disorder. *Language Speech and Hearing Services in Schools*. 2003; 34(3):180–193.
- Zayas, L., Rojas-Flores, L. Learning from Latino parents: Combining etic and emic approaches to designing interventions. In: Contreras, J., Kerns, K., editors. *Latino children and families in the United States: Current research and future directions*. Westport, CT: Praeger Publishers/Greenwood Publishing Group; 2002. p. 233–249.
- Zayas L, Solari F. Early childhood socializations in hispanic families: Context, culture, and practice implications. *Professional Psychology: Research and Practice*. 1994; 25(3):200–206.
- Zetlin A, Padron M, Wilson S. The experience of five Latin American families with the special education system. *Education and Training in Mental Retardation and Developmental Disabilities*. 1996; 31(1):22–28.

Zuckerman K, Sinche B, Cobian M, Cervantes M, Mejia A, Becker T, Nicolaidis C. Conceptualization of autism in the Latino community and its relationship with early diagnosis. *Journal of Developmental and Behavioral Pediatrics*. 2014; 35:522–32. [PubMed: 25186120]

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

Table 1

Demographic variables for quantitative-phase participants

	Parents			Children		
	Age in years	Median Education Level	Median Income	Age in years	Gender	Diagnostic Status
Non-Latino White	35.7 (SD = 4.4)	Associate's degree	\$80–100k/year	4.7 (SD = 1.3)	74% male	100% ASD diagnosis
Latino	36.3 (SD = 5.6)	High school diploma or equivalent	\$20–40k/year	4.4 (SD = 1.5)	75% male	86% ASD diagnosis 14% suspected ASD diagnosis

Table 2

Descriptions and video examples of intervention strategies provided in focus groups.

Name of Strategy	Description provided	Video examples	
<i>Prompting</i>	Prompting includes any help given to a child that assists him/her in using a specific skill or behavior. Prompting reduces incorrect responding as children acquire new skills by giving them as much help as is needed to perform a task, and then gradually taking away the help until the child can perform the task independently.	1	Physical prompt for sorting
		2	Gestural prompt for inserting a puzzle piece
		Descriptions of other targets for this strategy were provided	
<i>Modeling/Video Modeling</i>	Modeling involves the child observing someone correctly performing a target behavior. The demonstration of the behavior before the child is expected to demonstrate the behavior serves as a primer for the behavior. Modeling can be used as a prompt in order to provide extra support to the child after the direction has been provided and the child is trying to use the behavior. It can be used for any activity, like washing hands, eating, writing, pushing a chair under the table, or even communicating, like speaking or using an alternative system to communicate. Models can also be shown through video, where the child watches a video of the target behavior.	1	Model for functional play
		2	Video model for functional play
		3	Video model for taking turns
		Descriptions of other targets for this strategy were provided	
<i>Naturalistic Intervention</i>	A collection of practices including arranging the environment, following the child's lead, responding to the child's focus of interest, and embedding teaching time into daily routines. These practices are designed to encourage specific target behaviors based on the child's interests by building more complex skills that are naturally reinforcing and appropriate to the interaction.	1	Following the child's interest and joining in
		2	Arranging the environment and wait time
<i>Discrete trial training</i>	Discrete trial training is a one-to-one instructional approach used to teach skills in a planned, controlled, and systematic manner using small, repeated steps. Each trial or teaching opportunity has a definite beginning and end. The teacher gives an antecedent (instruction or cue for a behavior to start), waits for the child to perform the behavior, and then responds with a consequence/reward. Positive praise and/or tangible rewards are used to reinforce desired skills or behaviors.	1	Receptively identifying objects in a school setting
		2	Receptively identifying objects in a home setting
		Descriptions of other targets for this strategy were provided	

Table 3

Group means, standard deviations, and comparisons for surveys

	NLW	LSS	p-value	Cohen's d	
<i>FOS-R Outcomes</i>	Understanding your child's strengths, needs, and abilities	4.1	4.0	0.81	0.06
	Knowing your rights and advocating for your child	3.5	3.7	0.47	0.20
	Helping your child develop and learn	3.9	3.8	0.61	0.14
	Having support systems	3.7	3.4	0.26	0.31
	Accessing the community	3.8	3.3	0.10	0.45
<i>FOS-R Helpfulness Indicators</i>	Knowing your rights	3.3	3.5	0.51	0.18
	Communicating your child's needs	3.3	3.7	0.10	0.45
	Helping your child develop and learn	3.2	3.7	0.04*	0.57
<i>MPOC-20 Subscales</i>	Enabling and Partnership	3.5	4.1	0.11	0.42
	Providing General Information	2.9	3.0	0.76	0.08
	Providing Specific Information about the Child	4.1	3.9	0.57	0.15
	Coordinated and Comprehensive Care	3.9	4.1	0.53	0.17
	Respectful and Supportive Care	4.1	4.3	0.35	0.24

Table 4

Description of qualitative themes, subthemes, and topically related quantitative findings

Impact of Autism on the Latino Family	Stigma of ASD in the Latino culture	Families faced criticism and judgment from their community because of the persistent myth that autism is shameful and caused by the parents.	Autism making or breaking the family	Some families benefitted from a close knit Latino family and wished for more involvement in therapy from extended family. Most faced criticism and judgment from family members and had trouble maneuvering family conflicts.	Parents seeking social support elsewhere	Families attended support groups. They shared resources among each other and made connections with other participants. They felt group intervention may allow them to learn from and support each other.	Therapy priorities influenced by culture	When prioritizing therapy goals, caregivers had to balance between behaviors their child needed to function and how they would be viewed by their family, friends, and society in the future. Communication was the most common priority.	Significant quantitative findings	<ul style="list-style-type: none">LSS parents perceived less social support on 2 items in the <i>FOS-R</i>.
	No quantitative data on therapy strategies.									
Mix and Match Therapy Strategies	Variety of messages		Strategy's success worth the effort		Open to a variety of strategies		No quantitative data on therapy strategies.			
	Caregivers received various messages over time from a various sources and typically mixed and matched strategies for the moment or situation, often leaving them overwhelmed.		Caregivers preferred strategies that were effective for their child, regardless of culture or difficulty, though some caregivers gave up on strategies that were too difficult to maintain.		Caregivers were open to a variety of strategies and hesitated to choose a preferred option. They needed multiple strategies throughout the day.					
Unmet Needs from Service Providers	Involvement in therapy	Parents felt they were vital members of their child's intervention team and unanimously wanted more involvement, including observation time and training from therapists or teachers. More involvement was noted in private or home-based intervention as compared to school services.	Open Communication	Parents valued open communication. As primary caregivers, they had unique knowledge about the child that they wanted to be able to share with all service providers. Lack of English proficiency made it difficult for caregivers to build relationships with therapists and share information. They emphatically argued for more bilingual therapists.	Professionalism	Many caregivers experienced instances of unprofessional service providers. Parents then had to take a more leadership role in therapy than they would have liked.	<ul style="list-style-type: none">LSS parents rated intervention more helpful in teaching them "how to help their child develop and learn."LSS parents perceived more satisfaction in relationships with providers on two items in the <i>FOS-R</i>.LSS parents reported higher satisfaction with respectful and supportive care than being provided with general information.			

Table 5Comparison of selected individual items from the *FOS-R* between groups

Item	NLW	LSS	p-value	Cohen's d
Social Support Items				
Relationship Items				