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## Using the Ecological Validity Model to adapt parent-involved interventions for children with Autism Spectrum Disorder in the Latinx community: A conceptual review

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### ABSTRACT

**Background:** Parent involvement in interventions for children with Autism Spectrum Disorder (ASD) provides parents with education about ASD diagnosis and treatment, improves parent-child interactions, and offers access to cost-effective resources. The Latinx population represents the fastest growing minority population in the United States and a growing percentage of children seeking ASD intervention services.

**Aims:** Identify factors that impact Latinx parent involvement in interventions for children with ASD as an example of cultural considerations for diverse families and communities.

**Methods and procedures:** In this conceptual overview, we synthesize literature on cultural considerations for intervention design/adaptation for Latinx families and parent involvement in interventions for children with ASD through the lens of the Ecological Validity Model.

**Outcomes and results:** Frameworks such as the Ecological Validity Model can be used when creating or adapting interventions for specific cultural groups. Parent-involved interventions for children with ASD in the Latinx community should consider language of intervention delivery, family make-up, community support, disability knowledge of the family, the therapeutic alliance, and methods of implementation.

**Conclusions and implications:** Incorporating cultural components into parent-involved interventions will best support intervention implementation and dissemination in diverse communities. Research is needed into the process and outcomes of intervention programs in order to increase understanding of how specific cultural dimensions impact participation in and efficacy of parent-involved interventions for Latinx families of children with ASD.

### What this paper adds

Parent involvement plays an important role in interventions for children with Autism Spectrum Disorder. Parenting and parent

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involvement in interventions are impacted by cultural factors. This conceptual piece summarizes extant literature on parent-involved interventions for Latinx parents of children with Autism spectrum disorder. We identify and describe current research into interventions for this population and consider how specific cultural dimensions may impact Latinx parent involvement in interventions for children with Autism spectrum disorder. This piece provides directions for future research given the critical need to increase understanding of how cultural factors impact intervention participation and efficacy in order to improve outcomes for children with Autism spectrum disorder and their parents, as well as increase accessibility of evidence-based interventions for Latinx parents of children with Autism Spectrum Disorder.

## 1. Introduction

The Latinx community is the fastest growing culturally diverse population in the United States and a growing percentage of children seeking early intervention services (Maenner et al., 2016; US Census Bureau, 2019). The estimated prevalence of Autism spectrum disorder (ASD), which is characterized by impairments in social communication and restricted and repetitive interests beginning early in life (American Psychiatric Association, 2018; Park et al., 2019; World Health Organization, 2013), in the Latinx community in the US is 15.4 per 1000 (1.5 %) (Maenner et al., 2016). However, it is likely that Latinx children are under-diagnosed due to barriers to accessing diagnostic services (Liptak et al., 2008; Maenner et al., 2016). Multiple studies conducted in the US have indicated that young children with ASD benefit from early intervention services to support their behavior and social communication development (see Zwaigenbaum et al., 2015). Yet, Latinx children are diagnosed with ASD at later ages than children from non-Hispanic Caucasian populations and have a lower probability of receiving early ASD intervention services (Liptak et al., 2008; Magaña et al., 2013; Magaña et al., 2017; Mandell et al., 2009; Palmer et al., 2010). These disparities could have cascading effects as fewer early intervention services for families that speak languages other than English (Cohen & Christakis, 2006) may have a significant long-term impact for both families and children (Elder, 2016; Elder et al., 2017; Zwaigenbaum et al., 2015).

Parental participation in treatment is valued and sought after by parents and caregivers in the Latinx community when a child is diagnosed with a disability (DuBay et al., 2018). For example, Latina mothers of children with disabilities prefer to be involved in decisions about goals for their child and interact with the therapist during service delivery, especially when these services are provided in their homes (Núñez & Tejero, 2018). Latinx parents consider early intervention providers (e.g., Speech-Language Pathologists) to be a resource for supporting their child, and also believe that parents have a responsibility to support the child's needs in conjunction with the provider (Huer et al., 2001). However, there is a need for evidenced based research into culturally sensitive adaptations for interventions involving parents for children with ASD from diverse communities (Chambless et al., 1996; Hall, 2001; Lau, 2006).

There are theoretical reasons and some evidence that parents from diverse cultures will accept and benefit from adapted intervention supports. For example, evidence from research on intervention for children with Attention Deficit Hyperactive Disorder (ADHD) and disruptive behavior, suggests that parents from the Latinx community benefit from inclusion of specific cultural components into intervention programs to support increase in parent knowledge, acceptance of the services, and decrease in parental stress (Agazzi et al., 2010; Bauermeister, 2016). Identifying and systematically testing similar intervention adaptations for children with ASD could improve the way future supports for Latinx communities are created, adapted, and delivered.

Including parents in interventions helps to embed intervention strategies into everyday settings, which supports children in generalizing new communication and behavior skills across routines and contexts and dramatically increases in vivo learning opportunities (Koegel, 2000; McConachie & Diggle, 2007; Meadan et al., 2009). For parents, benefits of participating in interventions include increased positive parent-child interactions and parenting efficacy, greater knowledge of ASD and treatment strategies, increased parental buy-in, and access to a more cost-effective delivery model than direct treatment (Koegel et al., 1996; McConachie & Diggle, 2007; Solish & Perry, 2008; Zwaigenbaum et al., 2015). Despite the benefits of parent involvement in early intervention programs for children with ASD, the applicability and efficacy of established programs across cultures is unclear and the overwhelming majority of these studies have been conducted in the US with monolingual English speaking families (Mason et al., 2003; Prescott et al., 1999; Sheikh, 2006; Svensson, 1989). Also, some studies have systematically excluded participants who spoke languages other than English (Frayne et al., 1996; Murray & Buller, 2007). Cultural characteristics and context can shape parenting attitudes, parent-therapist relationships, and acceptance of support for children with ASD, and warrant consideration when implementing intervention with parent involvement.

In this conceptual piece, we integrate knowledge about parent involvement in interventions for Latinx families with a focus on applying these principles for families of children with ASD. Prior research demonstrates how cultural components impact parental involvement in interventions of children with ADHD (Matos et al., 2006; Matos et al., 2009) and language disorders (Peredo et al., 2018), but there is little research targeting families of children with ASD specifically. Acknowledging that parenting behaviors can fluctuate based on many contextual and situational factors, including cultural context, we aimed to address the following questions: 1) Are there existing interventions specifically designed/adapted for Latinx parents of children with ASD? 2) How do Latinx cultural and parenting attributes interact with intervention components when creating or adapting parent-involved interventions for families of children with ASD (Arim et al., 2012; Smetana, 2017)? 3) What are the implications of these findings for clinicians and researchers working with Latinx families of children with ASD? To address these questions, we applied the Ecological Validity Model (EVM; Bernal et al., 1995), which identifies eight key elements of interventions, as a framework in order to identify interventions and how components have been specifically designed/adapted for this population.

## 2. Using the ecological validity model to adapt parent-involved interventions for children with ASD

When developing an intervention for a specific cultural group, it is important to consider linguistic, contextual, and cultural backgrounds (Castro et al., 2010; Magaña et al., 2017; Parra Cardona et al., 2012; Valdez et al., 2013). Designing or adapting interventions requires decisions about the “what” of the intervention (i.e., informative components) as well as the “how” of the intervention (i.e., procedural components) (Baumann et al., 2015; Ferrer-Wreder et al., 2012). The Ecological Validity Model (EVM; Bernal et al., 1995) highlights eight cultural dimensions that may impact how an intervention is deployed for a given cultural group. This framework includes *language* used; attributes of *persons* involved and their relationship (i.e., therapist, parent, and child); incorporation of *metaphors* (i.e., symbols of the cultural group); consideration of *content* (i.e., cultural values and traditions) and *concepts* (i.e., theoretical orientation and intervention conceptualization); culturally-adaptive *intervention goals*; *methods/procedures* of intervention; and *context* of the intervention (i.e., economic, social, and community factors) (Bernal et al., 1995; Magaña et al., 2017).

Designing specialized culturally sensitive interventions is an iterative and collaborative process. Studies have used different approaches to design or adapt interventions, but, in general, researchers consistently identify a framework such as the EVM to guide their adaptation/design. The adaptation process may involve a case study or small cohort study (e.g., Buzhardt et al., 2016) and include group discussions with Latinx stakeholders including Latinx parents of children with ASD and relevant clinical providers (e.g., therapists, social workers, pediatricians) (Buzhardt et al., 2016; Chlebowski et al., 2018; Magaña et al., 2017). Parent interviews and group discussions/focus groups evaluate specific components of the intervention and provide feedback from the community on aspects of the intervention adaptations such as terminology, procedures, language, and other culturally relevant components (Chlebowski et al., 2018; Lopez et al., 2019; Magaña et al., 2017).

Although a systematic review is beyond the scope of this paper, we surveyed the literature by using research engines (e.g., PubMed, ASHAWIRE, and APA PsycNet) to identify available parent-involved ASD interventions in the Latinx community. We identified three interventions whose *primary focus* considered cultural components to best support participation of and for Latinx parents of children with ASD in the intervention<sup>1</sup>:

- a) *Online and Applied System of Intervention Skills* (OASIS; Buzhardt et al., 2016): OASIS (Buzhardt et al., 2016) is an intervention that teaches parents to implement applied behavior analysis (ABA) strategies with their children with ASD. OASIS uses a combination of online psycho educational modules, in vivo coaching, and video-conferencing. These approaches to intervention delivery were believed to improve accessibility of the intervention for Latinx parents.
- b) *Parent Taking Action* (PTA; Lopez et al., 2019; Magaña et al., 2017): PTA (Magaña et al., 2017) is a modular psychoeducational intervention delivered using a community health worker (promotoras de salud) model in families' homes (see below). PTA provides education about ASD, parent advocacy, and the service delivery system, as well as targeted behavioral strategies to support a child's positive behavior and communication. A recent small waitlist control trial of PTA suggested that this culturally tailored program may positively impact parent knowledge and confidence in using evidence-based behavioral strategies with their child, parent depressive symptoms, child service utilization, and child social communication skills (Lopez et al., 2019).
- c) *An Individualized Mental Health Intervention* (AIMHI; Chlebowski et al., 2018): AIMHI (Chlebowski et al., 2018) is a parent-mediated intervention that involves collaborative goal setting by the therapist and parent, psycho-education, and in vivo coaching in order to reduce challenging behaviors using applied behavior analysis (ABA) principles. AIMHI is conducted by trained therapists with parent participation, and has used both focus groups and individual parent and therapist interviews to identify future cultural adaptations from key stakeholders (Chlebowski et al., 2020).

Preliminary research into the design of these interventions for Latinx families of children with ASD highlights that the cultural adaptation components are critical for supporting parents' participation and engagement in the intervention (Buzhardt et al., 2016; Chlebowski et al., 2018; Magaña et al., 2017). Considering these studies, well as the broader literature into Latinx parenting culture and best practices for young children with ASD, we then used the Ecological Validity Model (EVM; Bernal et al., 1995) to conceptualize ways that intervention processes are tailored across the eight EVM dimensions to best fit Latinx families participating in parent-involved interventions for children with ASD.

### 2.1. Language

22 % of all U.S. Latinx children live in homes where their parents and caregivers speak primarily Spanish (Child Trends, 2018), which is potentially an important consideration when delivering culturally appropriate treatment in an English dominated country and when utilizing parent training materials developed for monolingual English speakers (Calzada & Eyberg, 2002; Dumas et al., 2011; Varela et al., 2004). Research investigating racial-ethnic disparities in ASD prevalence suggests that non-English primary language status may act as a barrier to ASD identification and access to services in Latinx families (DuBay et al., 2018; Liptak et al., 2008). Families stress the necessity of providers' language competence for communication with families; for example, a Latina focus group participant commented, “...above all, most important, they [service providers] have to be *bilingual*...” (DuBay et al., 2018, p. 1632). It

<sup>1</sup> Several other studies of parent-involved interventions for ASD have included Latinx families in the sample population but these interventions and studies were not explicitly designed with cultural needs in mind (e.g., Carter et al., 2012; Dawson et al., 2010; Pennefather et al., 2018; Stahmer et al., 2020).

can greatly reduce disparities of early services for children if families can communicate appropriately with providers and understand the content in discussion (Saha et al., 2007; Steinberg et al., 2016). For example, a Latina mother of a child with ASD participating in a focus group on early intervention services reported “I had a good experience with them [bilingual service providers] 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.” (DuBay et al., 2018, p. 1632). Interventionists should also use culturally relevant language that is at an educational level consistent with the parent’s language understanding when explaining sensitive information (e.g., diagnosis, children’s difficulties) and to increase parent understanding of complex content (i.e., avoid jargon/technical terms; Buzhardt et al., 2016; Chlebowski et al., 2018). Providing glossaries that define terms and using written and verbal examples may also be helpful as was recommended by participants in AIMHI (Chlebowski et al., 2018).

There continues to be many misconceptions about the impact of multiple language exposures for children with ASD and how this impacts intervention delivery. An extensive literature indicates that bilingual or multilingual households are beneficial for children’s language and cognitive development, including for children with ASD (Conner et al., 2020; Hampton et al., 2017; Lee et al., 2015; Velázquez, 2009). For example, bilingual Spanish-English speaking children with ASD had higher pre-verbal communication skills such as gestures than monolingual children (Valicenti-Mcdermott et al., 2013). Several studies indicate advantages in expressive vocabulary and social use of language in bilingual children with ASD (Hambly & Fombonne, 2012; Hambly & Fombonne, 2014; Peterson et al., 2012). However, societal stigma surrounding bilingualism in early intervention contexts persists and it is not uncommon for practitioners to recommend monolingual English support services for these children (Ijalba, 2016; Lee et al., 2015; McDaniel et al. 2019; Torres Beltran, 2019). Ijalba (2016) described parent comments towards this matter: “Where I work, there is a school across the street and many teachers come to the diner and I talk to them. I asked them what to do with Andrés and they told me to only speak English with him” (Ijalba, 2016, p. 208). Additionally, some mothers worry about teaching children their mother tongue “I think if he speaks Spanish, he will not learn English, he may get confused” (Ijalba, 2016, p. 208).

At the same time, many parents state that knowing and understanding their mother tongue (Spanish) is important for interactions with the family and shows respect for their culture (Lee et al., 2015). “You have to make their foundation strong, to be proud of where they are from, who they are ... and then everything is fine.” (Lee et al., 2015, p. 5). Insisting that intervention be conducted exclusively in English may inadvertently further isolate a child with ASD from their immediate and extended family. It may also make it more challenging for parents to employ strategies from the intervention into their everyday interactions with their child in the home setting, which is frequently a goal of parent-involved interventions (Schreibman et al., 2015). For interventions to be appropriate for a specific cultural group, communication should be conducted and materials should be written in their primary or preferred language in order to decrease communication barriers and increase parent participation opportunities such as advised in PTA (Magaña et al., 2017).

Overall, studies have found that language modification increases acceptance of the intervention, knowledge about the disability, supports higher intervention retention rates, and increases the likelihood of treatment uptake for the family (Lopez et al., 2019; Magaña et al., 2017). Therefore, language is an essential component to many successes in adapted or designed programs for the Latinx parents and their children with ASD.

## 2.2. Persons

Parent-involved interventions involve, at a minimum, the therapist, parent, and child. Attributes of each person involved and their relationship with each other can impact the intervention experience. Establishing rapport between therapist and participants is important for supporting families in their involvement in an intervention. This is of course always the case in building therapeutic relationships (Buzhardt et al., 2016; Reeder & Morris, 2018) though particular consideration must be given when there are cultural and/or language differences between therapist and parent, which might contribute to conflicting beliefs about how parents and therapist perceived parental involvement (Chlebowski et al., 2018). For example, in AIMHI (Chlebowski et al., 2018), focus groups and interviews were conducted with therapists and Latinx parents about their experience in a parent-mediated mental health intervention for children with ASD. There was an expressed need for clear communication about expected involvement and role of the parent and therapist (Chlebowski et al., 2018). Parents frequently spoke of the need for *personalismo*, or the development of personal connections between parents and therapists based on expressions of interest in and understanding of their family (Chlebowski et al., 2018). The development of *confianza*, or trust and respect, is also fundamental to building a supportive relationship (Anez et al., 2008; Chlebowski et al., 2018). Such elements increase parents’ comfort in actively participating in therapy sessions. Some research has also identified *respeto*, a cultural value that includes deference and respect for authority, as impacting parent engagement and the parent-therapist relationship (Anez et al., 2008; Calzada, 2010).

Parent-involved therapy for children with ASD need not be limited to only one participating parent. The concept of *familismo* is used when describing cultural characteristics of the Latinx community because it reflects the importance of family relationships, and the comfort and security that these relationships provide (Ayón et al., 2010; Parsai et al., 2009). Latinx families tend to be supported by a large group of immediate and extended family members and consider children as a very important part of the household (American Community Survey, 2008; National Alliance for Hispanic Health 2004; U.S. Census, 2008). Although mothers often assume the role of primary caregiver, children in the Latinx community may be raised by multiple caregivers and exposed to different types of behaviors, social engagements, and relationships (Cabrera et al., 2012). When surveyed about experiences in early intervention, Latinx parents of children with ASD expressed the desire to include this wider family support system in their child’s intervention (DuBay et al., 2018). This matter was highlighted and suggested in OASIS, where researchers explained how inclusion of other family members in intervention may increase the likelihood of intervention participation and completion (Buzhardt et al., 2016).

Beyond the immediate household, Latinx parents often rely on outside communities such as family friends and religious gatherings

for bonds of support (Ayón & Naddy, 2013). These bonds tend to have a significant impact on parenting and beliefs about child development. Latinx mothers express that one of the challenges of navigating the ASD diagnostic process includes the stigma and resulting social isolation from extended family members or the local community (Blanche et al., 2015; Lobar, 2014; Zuckerman et al., 2014). Indeed, parents of children with ASD experience heightened stress and mental health difficulties (Vasilopoulou & Nisbet, 2016). One possible approach to building community support into parent-involved interventions is through the use of a *promotoras de salud* model as used in PTA (Magaña et al., 2017). In this model, community members of similar backgrounds are trained to provide intervention components. For example, one study of PTA reported that the inclusion of *promotoras* who were primarily Spanish speaking and who also had a child with ASD or similar developmental disability helped to retain families and parents' participation in the intervention (Magaña et al., 2017). Another approach could include parent groups for psychoeducation and parent coaching in intervention strategies; Latinx parents may participate in support groups with other parents of children with ASD and have expressed interest in group training approaches that would also provide community and support (DuBay et al., 2018). Interventions should therefore consider how broader extended family and community networks are integrated into interventions to best support parents and their children with ASD.

### 2.3. Metaphors

When creating materials and discussion sessions with parents, cultural specific proverbs/sayings and idioms, called *dichos* in Spanish, can be considered (Bernal et al., 1995; Magaña et al., 2017). The use of *dichos* is a way of aligning with regions or countries' culture and differences and provides a colloquial way of explaining concepts with phrases that the population understands (Hou, 2013; Saddhono et al., 2019; Schuster, 1998). Incorporating sayings into the protocols and manuals of an intervention could help signal to parents knowledge of and respect towards their culture. An example of the use of *dichos* was presented in designing PTA (Lopez et al., 2019; Magaña et al., 2017). They incorporated sayings into their psychoeducational manuals in relation to the topics discussed. For example, they used "poco a poco, se andan lejos" ("little by little, one goes far") (Magaña et al., 2017, p. 61) to reference the intervention process of skill building. Magaña and colleagues also incorporated storytelling into their PTA manuals, which reflected the skills that were being taught in more relatable formats. Magaña and colleagues suggest in PTA that aligning parent training with culturally ubiquitous storytelling themes provides an existing adaptable platform for parents to engage in the intervention. However, researchers and clinicians should understand that sayings and story themes can vary from one culture to the next and might be accepted differently according to the target population (Hou, 2013; Saddhono et al., 2019; Schuster, 1998). Therefore, it is important to be informed about the target population and determine the appropriate language and sayings to use accordingly.

### 2.4. Content and concepts

Parent-implemented interventions often include psychoeducational components regarding ASD and intervention strategies and may also involve coaching and feedback in specific intervention techniques (Peredo et al., 2018; Schreibman et al., 2015). Culture may interact with the content and theoretical orientation (concepts) of parent-involved interventions in multiple ways, including the variability of experiences parents may have had with the diagnostic process and access to interventions, as well as the general knowledge and perceptions of Latinx parents toward individuals with disabilities broadly and ASD specifically (Blanche et al., 2015; Lobar, 2014; Zuckerman et al., 2014). Many Latinx parents report challenges with navigating the process of obtaining an accurate diagnosis and beginning intervention for their child (Zuckerman et al., 2014). Parents perceive that providers may dismiss parents' concerns about the child's development and may feel that they have limited power to advocate for them (Zuckerman et al., 2014). Latina mothers also report that a diagnosis related to special needs can be "scary" and difficult to understand and express a need for support and education about the diagnosis (Tejero Hughes et al., 2008).

In surveys of Latinx mothers of children with ASD, respondents often expressed that they did not know about ASD until after their child was diagnosed (Ijalba, 2016; Zuckerman et al., 2014). In the AIMHI intervention, Latinx mothers voiced a need for greater psycho-education about ASD when beginning a parent-involved therapy for their child with ASD (Chlebowski et al., 2018). Some studies found that parents of Latinx backgrounds think of a disability diagnosis as an illness, something temporary, or blame themselves for their child's diagnosis (Ijalba, 2016; Lobar, 2014). At the same time, mothers have expressed that children with disabilities are positive in their lives (Tejero Hughes et al., 2008).

Therefore, successfully involving Latinx parents in interventions must consider their history with the diagnostic process and should incorporate education about ASD and how the diagnosis connects with the intervention goals and strategies. Interventionists interviewed by Chlebowski et al. (2018) in AIMHI explain how "... it's about going back to the beginning, it's to make the parents understand, give them an explanation...What are autism's key points?... and that they can understand it, the children's actions, reactions, and behaviors." (Chlebowski et al., 2018, p. 557) AIMHI researchers included psychoeducational components about the ASD diagnosis into their materials before starting to teach the intervention strategies (Chlebowski et al., 2018). The authors note that this could increase conceptual understanding about ASD and therefore reduce parental stress and self-blame towards their child's diagnosis (Chlebowski et al., 2018). Educational components can be incorporated as "anchoring activities" (Magaña et al., 2017) in which the content is presented in multimodal formats (e.g., through inclusion of picture or video models) that provide opportunities for active discussions with parents (Magaña et al., 2017).

## 2.5. Goals

Goals of parent-involved interventions for children with ASD may vary based on the specific intervention and will relate to factors such as the intervention context, concepts, and content. In parent-involved interventions, goals may involve parent behaviors such as parents demonstrating fidelity with delivering specific intervention strategies and may require families to engage in home practice activities (Magaña et al., 2017; Carter et al., 2012; Chlebowski et al., 2018; Peredo et al., 2018). Goal setting should be a collaborative process between persons involved in the intervention (see Brewer et al., 2014; Costa et al. 2017). Cultural factors may arise in regard to setting goals and communicating expectations about them; for example, Latinx parents participating in AIMHI noted the need for therapists to support parents by creating brief home practice assignments, which are set up in ways that enable families to be successful in reaching the goal targets (Chlebowski et al., 2018).

Increasing the child's communication is a common goal for children with ASD but cultural factors may impact acceptability of communication strategies (e.g., focus on spoken language only versus use of sign language or visual supports; DuBay et al., 2018). For example, mothers may not understand the need for their young children to be speaking because the parents did not speak until later, impacting their acceptance of a goal that targets word expression (e.g., "My son's father spoke when he was 5 years old and he is well, he does not have problems"; Ijalba, 2016, p. 207). Goals may also consider the family system more broadly such as targeting family well-being or helping families participate in community activities (Estes et al., 2019; Magaña et al., 2017; Matos et al. 2006; Wainer et al., 2017). In Latinx families, such goals may be meaningful and consistent with the emphasis on *familismo* and community. As presented in PTA, *familismo* can also be a way of establishing rapport with parents and empowering them to advocate for their children (Magaña et al., 2017). Regardless of the specific goal, clear communication is imperative so that therapists and parents are in agreement about intervention targets; parental buy-in for goal setting may both directly and indirectly support children's development through impacting parent engagement in the intervention.

## 2.6. Methods

Broadly speaking, parent involvement in interventions may be particularly well suited for young children with ASD (Garbacz et al., 2016; Hampton & Kaiser, 2016; Ingersoll & Wainer, 2013; Rogers et al., 2014; Shire et al., 2016) and generally aligns with Latinx cultural beliefs that place a prominent involvement of the family (and frequently mothers) in children's care (DuBay et al., 2018). Methodology of implementation for specific parent-involved interventions varies because each program targets different skills or combinations of goals across domains (e.g., child communication, play, behavior). However, common methodological themes emerge across various intervention adaptations for Latinx families of children with ASD, which tie into the above-mentioned components. For example, the OASIS and AIMHI interventions suggest expanding intervention duration and providing additional time for psycho-education about ASD, intervention goals, and coaching procedures, potentially as a response to limited parent education about ASD (Buzhardt et al., 2016; Chlebowski et al., 2018; Perry et al., 2005; Yeh et al., 2004). Expanding intervention duration may also provide more time for Latinx families to establish rapport with the therapist (Buzhardt et al., 2016; Chlebowski et al., 2018). Programs also may benefit from having additional modalities of presenting information such as visuals and video modeling to demonstrate intervention strategies (Buzhardt et al., 2016; Chlebowski et al., 2018). These complementary modalities may be particularly relevant in care of interventions for families of children with ASD as children with ASD may benefit from such intervention support (e.g., video-models: Corbett & Abdullah, 2005).

## 2.7. Context

Intervention context refers to larger framing in which the intervention is delivered, which may include developmental, cultural, economic, and societal lenses (Bernal et al., 1995). Involving parents in interventions for children with ASD aims to be responsive to the developmental context of children's skill development given the important role of parents as social partners to their children (Schreibman et al., 2015). Parent-involved interventions designed for children with ASD from Latinx families have also aimed to be contextually appropriate through different modalities of delivery that are sensitive to families' comfort level and needs. For example, approaches like the OASIS intervention, have included online/remote delivery (Buzhardt et al., 2016) and other approaches, including PTA, focus on delivery in participants' homes (Lopez et al., 2019; Magaña et al., 2017). Such approaches may appropriately support Latinx parents, including improving accessibility, creating a trustworthy parent-therapist relationship, and providing additional treatment sessions to gauge parent attitudes and goals (Buzhardt et al., 2016; Chlebowski et al., 2020; Magaña et al., 2017). As noted above (Persons section), interventions for Latinx parents have also considered sociocultural preferences through harnessing community support and relationships such as with the *promotoras de salud* model used in the PTA intervention (Magaña et al., 2017). There are also efforts to deliver evidence-based parent-implemented interventions for children with ASD through publicly-funded early intervention service delivery systems, which frequently serve Latinx families (e.g., Stahmer et al., 2020). However, interventions delivered through this context likely still require adaptations to best meet the needs of Latinx parents such as demonstrated by the AIMHI program, which was delivered through publicly-funded mental health services but required cultural adaptations for Latinx families (Chlebowski et al., 2018; Stahmer & Brookman-Frazee, 2019).

## 3. Discussion

As noted above, parent involvement in early intervention services for children with ASD has increasingly become a standard

practice with benefits to both children and parents (Garbacz et al., 2016; Hampton & Kaiser, 2016; Ingersoll & Wainer, 2013; Rogers et al., 2014; Shire et al., 2016). The exact nature of parent involvement varies across specific interventions, but ubiquitous approaches include parent education about ASD and intervention approaches, parent coaching in intervention strategy implementation, and/or parents as collaborative partners in intervention goal setting (Koegel et al., 2019; Green et al., 2010; Ingersoll & Gergans, 2007; Ingersoll & Wainer, 2013; Shire et al., 2016; Zwaigenbaum et al., 2015). Despite the plethora of parent-involved interventions for children with ASD, only very few of these interventions have been specifically designed or adapted with consideration of Latinx families' cultural background.

This conceptual synthesis considered cultural components that may impact Latinx parent involvement in interventions for children with ASD. Aligned with the EVM, we noted several areas of particular relevance for parent involvement as culture impacts parenting practices, beliefs, and knowledge, and parents' relationships with their child and service providers. In regard to designing culturally-tailored parent-involved interventions for children with ASD, studies to date have particularly noted the importance of considering language of intervention, incorporation of extended family and community, the parent-therapist relationship, acknowledging family history with the diagnostic process, parent knowledge about ASD, and intervention methods. Designing interventions that consider these cultural dimensions may increase parents' and families' participation in intervention and increase intervention efficacy for children with ASD and their parents (e.g., Buzhardt et al., 2016; Chlebowski et al., 2018; Magaña et al., 2017). Directly addressing cultural components aligns with the need to make parent-involved interventions for children with ASD more accessible for families by focusing on how to best support family functioning (Stahmer & Pellacchia, 2015). Here we discuss additional elements for consideration when delivering interventions for Latinx families as well as some directions for additional research.

### 3.1. Providers

In addition to having evidence-based intervention programs that are culturally adapted for Latinx parents, it is also necessary to have providers who can deliver the intervention. Educating therapists is an important component when offering services to parents and children from the Latinx community or other cultures (Chlebowski et al., 2018; Yu, 2013). Intervention programs may want to include training components or psychoeducational modules for providers in order to strengthen their cultural competency and humility and support their work with Latinx families. For those interventionists who are currently using established programs, it is highly recommended for them to consider different components they might want to modify in order to make their intervention more culturally appropriate. Clinicians can use the EVM to guide their modifications and potentially result in more buy in by parents or caregivers.

As noted previously, whenever possible, families should complete the intervention in their primary language. It can greatly reduce disparities of early services for children if families can communicate appropriately with providers and understand the content in discussion (Saha et al., 2007; Steinberg et al., 2016). In many cases, it may be appropriate for practitioners to provide bilingual instruction. In cases where a family requests monolingual English intervention, clinicians should ensure that the family request for monolingual English intervention is not predicated on a misunderstanding of the literature on monolingual and bilingual intervention. In many locations in the USA, the availability of bilingual or Spanish speaking therapists/providers is limited, but parents can still be encouraged to use their home language when using strategies with their child and be educated about the benefits of maintaining the home language and of bilingualism. For example, interventionists can inform parents about studies demonstrating positive effects of bilingualism for children with ASD in regard to gestures and expressive vocabulary development (Hambly & Fombonne, 2014; Valicenti-Mcdermott et al., 2013). It might also be beneficial to ask parents to reflect on their goals for their child, which likely include supporting the child in communicating with parents and family members. The interventionist can help parents consider if speaking to their child in their native language might increase the amount or quality of their social interactions with each other. In a qualitative study of three multilingual families, parents perceived their interactions with their child with ASD to be stronger when conducted in their native language (Jegatheesan, 2011). Promoting appropriate exposure and educating parents about the evidence in support of bilingualism for children with ASD might increase parents' confidence regarding their language use at home.

Intervention designs could also consider other intervention methods. For example, Latinx parents have expressed interest in parent group approaches (e.g., DuBay et al., 2018), which could enable more parents access to Spanish-speaking or bilingual therapists. Parent group components can involve psychoeducation and coaching (e.g., reviewing videos and providing feedback), as well as creating a supportive community experience. Alternative delivery approaches such as telehealth could also increase access to linguistically and culturally competent providers; telehealth approaches that include both online didactic training and interactive coaching opportunities are increasingly being evaluated for parent-involved interventions for children with ASD (see the systematic review in Sutherland et al., 2018). Intervention programs may also partner with community members to deliver care such as in the *promotoras de salud* (community health workers) model (Lopez et al., 2019; Magaña et al., 2017).

Taking steps to ensure ongoing communication between therapist and parents may also be critical. As noted in Chlebowski et al. (2018), there can be a disconnect between parent and interventionist perceptions of parental involvement and participation in therapeutic sessions. Therefore, interventionists should be encouraged to regularly check in with parents, review expectations, establish goals, and promote participation. This type of communication is especially important at the beginning of the program, because it can promote positive rapport, confidence, and buy-in.

### 3.2. Heterogeneity

It is important to recognize that some of the cultural components discussed in this paper might not be applicable to every Latinx community and that the successful integration of these components must take into account the attributes of the specific participating

community. For example, although modification of language content of interventions might be generally applicable, there may be specific vocabulary or idioms for particular communities that require additional adaptation. At the same time, while the focus of the current paper is Latinx families, some cultural adaptations presented here may be beneficial for families from diverse cultures (e.g., increased psychoeducation; use of video models) but may require culture specific refinements.

### 3.3. Research directions

In regard to next steps, while a growing body of research highlights the development process for designing and adapting interventions for parent-involved interventions for children with ASD, there is limited research on the efficacy of specific intervention programs for Latinx parents and their children. Large scale, randomized trials are needed to assess short- and long-term outcomes of specific parent-involved intervention designs for Latinx families of children with ASD. Examples of research outcomes that have been reported for parent involved interventions more generally include increasing positive parent-child interactions, increased parenting efficacy, reduced parent depression, and increased child communication/skill development (Lopez et al., 2019; Magaña et al., 2017; Matos et al., 2009). Research over the last several years has highlighted the importance of considering outcomes for both children and parents in ASD interventions and considering the inter relationship between child and family factors in therapeutic outcomes (Karst & Van Hecke, 2012). Outcome measures should target skills or goals that are meaningful for families and thus may involve child (e.g., verbal and nonverbal communication), parent (e.g., stress, efficacy), or community level variables (e.g., service utilization; community participation; community support). Studies investigating the agents of change or active ingredients of interventions are needed in order to determine how cultural components of interventions directly or indirectly impact outcomes for parents and children (e.g., increasing parent knowledge of ASD or utilization of specific intervention strategies; increasing parent-therapist alliance).

There is also potential to expand research into culturally adapted interventions for ASD by considering interventions previously adapted for Latinx families of children with other diagnoses. For example, Parent-Child Interaction Therapy (PCIT; Matos et al., 2006) is a behavior management intervention that has been successfully adapted for Latinx parent-child dyads with children with ADHD (Matos et al., 2006; Matos et al., 2009). PCIT has also been used for behavior challenges in children with ASD (Lesack et al., 2014; Masse et al., 2007; Masse et al., 2016; Solomon et al., 2008) because it includes parenting strategies such as parental responsiveness to reinforce child positive behaviors that align with intervention approaches in ASD. Thus, researchers could draw upon parent-implemented programs already successfully adapted for Latinx families of children with other conditions and consider if these adapted programs are also appropriate for Latinx families of children with ASD.

Focus should also be given to cultural training programs for providers in order to enhance the skill sets of providers already working with diverse families. For example, as reported by Ijalba (2016), parents expressed that (some) interventionists are recommending that parents speak to their children in English; this conflicts with best practices, which support bilingualism in service provision (Lee et al., 2015; Velázquez, 2009). Given misconceptions from both interventionists and family members about the use of bilingualism (Ijalba, 2016), combined with findings from the EVM framework that suggest a need for more psychoeducation in interventions for Latinx families of children with ASD, interventionists could provide education to parents about language development in bilingual homes. The development and evaluation of training programs are needed to help providers acquire and use skills to better support diverse populations.

Additionally, future intervention studies should include diverse populations in their participant cohorts and report demographic information in publications. In a recent extensive literature review of 634 intervention studies for individuals with ASD, 69.7 % of the studies did not report race/ethnicity/nationality (Steinbrenner et al., 2020). Without being provided racial/ethnic demographic information for ASD intervention studies, readers are unable to contextualize study results into their own communities, negatively impacting generalizability.

## 4. Conclusions

Parent involvement plays an important role in interventions for children with ASD, including in the Latinx community. Parenting and the experiences of parents are impacted by cultural beliefs and knowledge. In order to best support Latinx families' of children with ASD, parent-involved interventions should be adapted based on cultural considerations that impact both the content and methods of the intervention. There is a critical need for additional research into the process and outcomes of these intervention programs in order to increase understanding of how specific cultural dimensions impact intervention participation and efficacy, as well as to improve outcomes and accessibility of evidence-based interventions for Latinx families of children with ASD.

### Declaration of Competing Interest

The authors report no declaration of interest.

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