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FORUM ON DIVERSITY AND INCLUSION

Understanding the Role of Cultural Values in ABA Service Delivery: Perspectives from Latino Families

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Abstract
The purpose of this study was to identify and learn about the cultural and language barriers that Latino families face when accessing applied behavior analysis (ABA) services for their children with autism spectrum disorder (ASD). We administered a survey to gather basic descriptive information regarding language and cultural barriers faced by Latino families, specifically from a sample of families living in Nevada. We then conducted follow-up interviews and focus groups to collect detailed accounts of the barriers that these families faced. We used qualitative research methods to provide a detailed analysis that captured the voices of the families who participated in this study. The information provided from the survey and focus groups provides preliminary information for practitioners to help bridge gaps and provide more effective and quality services for the Latino population. Results of the focus groups and interviews are summarized and implications for future research are discussed.

Keywords Latino · Cultural values · Multilingual diversity · ABA service delivery · Autism spectrum disorder

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We would like to provide some important background information given the topic of the manuscript. MCH, IK, and LVL all identify as Latinas and Spanish-English bilingual females. BPC identifies as a White female English speaker.

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As one of the fastest growing communities within the United States (US), it is expected that by 2045, the Latino[1] population will grow up to 24.6% (Frey, 2018). As a population, it is projected that Latinos will make up 28% of the total US population by 2060 (US Census Bureau, 2018). The Latino population represents a large group of individuals originating from over 20 countries, including Central and South America, Cuba, Mexico, Puerto Rico, among others (Office of Management & Budget, 1997). In the US, the majority of Latino subgroups include those who identify as Mexican (64%), followed by Puerto Ricans (9.4%; Motel & Patten, 2012). The Latino population varies significantly by each state in the US. In particular, Nevada has one of the largest Latino populations in the US, ranking 5th nationally at 29% (US Census Bureau, 2021; Wee, 2018).

Despite the large representation in numbers, Latinos continue to face barriers in access to healthcare, including behavioral services. According to the Behavior Analyst Certification Board (BACB; n.d) most certified behavior analysts work in the area of autism providing behavioral services. However, it is unclear how many of the services that are being provided by behavior analysts are being accessed by the Latino community. A prevalent barrier among Latino families is obtaining an autism spectrum disorder (ASD) diagnosis for their children in order to receive behavioral services. While the national prevalence of ASD is currently 1 in 44 children in 2018, the current estimate for Latino children is lower (Maenner et al., 2021).

Language can furthermore play a critical role in this setting. For example, issues may arise if Latino families are trying to communicate their concerns in the Spanish language and professionals are unable to comprehend family concerns. It is important to stress that limited English proficiency and bilingualism are not inherently barriers in and of themselves. The barrier arises when there are differences in language proficiency between the practitioner and the family receiving services. Thus, the barrier lies within the service delivery system, as there are not enough bilingual professionals to help guide families who need support in the Spanish language (Lanesskog et al., 2015; Ruiz-Adams, 2019). Another barrier that is often faced by Latino families is a lack of knowledge and information about ASD (Zuckerman et al., 2014). Increasing Latino families' knowledge of ASD can also guide families to find interventions derived from applied behavior analysis (ABA) that are empirically supported (National Autism Center, 2015).

Unrecognized differences in the cultural practices between service providers and the recipients of those services is an additional barrier. Culture is always changing and influences families differently (Magaña, 2000). Cultural values may influence how families interpret their child's diagnosis, decisions regarding whether or not to pursue treatment, the selection of and preference for treatment providers, methods, and goals, and the continuation of services once initiated (Buzhardt et al., 2016; Pitten, 2008; Smith et al., 2011). In addition, cultural values and practices are critical

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[1] While the term *Latinx* is currently considered to be a progressive and inclusive identifier (Scharrón-del Rio & Aja, 2020), the authors elected to use the term *Latino* throughout this manuscript. The authors believed that the term *Latino* would be a better representation because when working directly with the families in the study, the term *Latino* was primarily used due to the familiarity and preference indicated by the families.

during the intervention process as they may influence adherence to treatment (Slim & Celiberti, 2021). This barrier lies in a system that is not able to readily adapt to the needs of a population and account for such differences (Ferguson & Vigil, 2019).

From a behavior analytic perspective, culture can be defined as behaviors of a particular group that are maintained as a result of social reinforcement (Skinner, 1984). Culture impacts the way we use the science of behavior, such as changes in the topography of our interventions. Furthermore, individuals can use their culture to adapt and transform their environment (Lavenda & Schultz, 2010). Cultural values and beliefs are always part of the context in which behaviors occur, and thus, influence patterns of behavior.

Understanding cultural values in the Latino community can be critical when providing behavioral services. For example, learning about a family's culture can help practitioners understand how certain sets of values and beliefs fit within their broader context (Neely et al., 2020; Slim & Celiberti, 2021). In addition, by recognizing a family's cultural values, behavior analysts can address disparities in access to services (Castro-Hostetler et al., 2021; Neely et al., 2020). Each family brings their own set of cultural values that is unique for their environment, underscoring the importance of service providers developing flexibility skills (i.e., cultural responsiveness) and learning to apply what is needed within the context for each family (Williams, 2021). While behavior analysts should avoid stereotyping cultural beliefs with families or assuming families hold certain cultural values based on their racial and ethnic identity (Neely et al., 2020), there is also risk in ignoring cultural values in service delivery.

Given the diversity and different subgroups in Latino families, there is no "set list" of values that will apply to all groups. However, there are some cultural values and practices that are likely shared across Latino families (Garcia-Preto, 2005; Santiago-Rivera 2003). The literature demonstrates a tendency for more collectivist values than individualistic centered values (Dingfelder, 2005). Research suggests that some of those shared values and constructs include familismo (familism), personalismo (friendliness), and confianza (trust; Añez et al., 2008; Juckett, 2013; Magaña, 2020). Although this is not an exhaustive list, we briefly discuss these values here and explore how they can pertain to the context of the delivery of ASD services for Latino families.

Cultural Values and Practices

Familismo (Familism)

The value of familismo refers to values and behaviors around inclusiveness, participation, and a strong bond in nuclear and extended family networks that reflect the way family ties are prioritized (Falicov, 1998; Hernández & Bámaca-Colbert, 2016; Marsiglia et al., 2013). Familismo may involve sharing critical responsibilities such as involvement in important decision making, caretaking, and emotional support (Sabogal et al., 1987). Therefore, when providing behavioral services, Latino families may request for extended family members (e.g., grandparents) to be included in meetings and parent trainings. Furthermore, Latino families may also request goals that are centered around family traditions or values.

Personalismo (Interpersonal Relationships)

Personalismo can be discussed as creating a personal relationship rather than an institutional relationship (Juckett, 2013; Magaña, 2020). In efforts to establish an interpersonal connection, Añez et al. (2005) recommends that throughout treatment, providers spend at least 5 min at the beginning of the session building rapport. Similarly, Jimenez-Gomez and Beaulieu (2022) discuss the importance of building rapport during the assessment process by using cultural humility and engaging in perspective taking skills with families. Ultimately, this concept will begin to establish a sense of respect from the family's point of view and understanding of the working relationship moving forward.

Confianza (Trust and Intimacy in a Relationship)

The value of confianza is often built into the other discussed values held by Latinos and can be essential to clinical engagement practices (Falicov, 1998; Santiago-Rivera 2003). Confianza refers to a sense of trust and intimacy within the created interpersonal relationships (Bracero, 1998). In the context of providing ABA services, this can present itself by families coming in and requesting services from a specific practitioner because of a family or friend's recommendation. Service providers should be aware that building trust can take time to develop and is an ongoing building experience.

While the above listed barriers and cultural barriers might be held by many Latinos, it is inappropriate to assume that this is the case for every family or individual. Furthermore, there are likely differences in the way that families experience a barrier or engage with a value. Therefore, it is worthwhile to directly engage with Latino families of children with ASD to learn about the barriers they face and the values that they hold as it relates to behavior analytic treatment.

The purpose of this qualitative study was to learn about the cultural and language barriers that are faced by Latino families when accessing ABA services for their children with ASD, specifically from a sample of families living in Nevada. This was a two-part study; part one was the Participant Demographic and Experience Survey, and part two was centered on the structured interviews and focus groups. The aim of the focus groups was to explore the quality of behavioral services Latino families from Nevada are receiving. Specifically, we aimed to examine the role that cultural values played in family centered planning and treatment services for Latino parents.

Method Study 1: Demographic and Experience Survey

Recruitment and Participants

We recruited participants through local community partners, ABA-based agencies, and organizations that serve children and families with developmental disabilities. We distributed recruitment flyers directly to families and through online platforms such as social media pages (i.e., Facebook) and community pages. In addition, we

Table 1 Sociodemographic characteristics of online survey participants

Characteristic	N	%	Characteristic	N	%
Gender			Hispanic/Latino origin		
Female	16	89	Mexican	16	89
Male	2	11	Central American	1	5.5
Age			Puerto Rican	1	5.5
25–34	3	17	Education level		
35–44	15	83	Did not graduate	1	5.5
County of NV residence			High school diploma/GED	7	39
Clark	5	28	Some college/associate	5	28
Washoe	13	72	Technical degree	1	5.5
Ethnicity			Bachelor's degree	1	5.5
Hispanic/Latino	18	100	Graduate/professional degree	2	11
Language spoken in the home					
English	5	28	Other	1	5.5
Spanish	6	33			
Both equally	7	39			

N = 18. Participants were on average 36.4 years old

distributed flyers in English and Spanish. Furthermore, we sent recruitment information via email to approximately five to ten community partners to be shared with families. Families were included to participate in the survey if they met the following criteria: (1) respondent was 18 years or older, (2) identified as Hispanic/Latino/a/x, (3) had at least one child diagnosed with any developmental disability, and (4) currently received or had received ABA services in the past.

Eighteen Latino parents participated in the Demographic and Experience Survey. Eight (45%) of the participants completed the survey in English and ten (55%) completed the survey in Spanish. Aggregated participant demographics are presented in Table 1, including the parents' cultural identity, their primary language spoken in the home, and parents' educational level. The majority of parents ($n = 16$, 89%) reported Mexican being their cultural identity. Ages ranged from 25–44, with an average age of 36 years old. Parents reported a range of responses for their primary language spoken in the home; ($n = 7$, 39%) of parents reported speaking English and Spanish, followed by primarily Spanish ($n = 6$, 33%) and then English ($n = 5$, 28%).

Survey Instrument and Data Collection

Participant Demographic and Experience Survey In the Participant Demographic section, we asked participants about their gender identity, age, what primary language is spoken in the home, county of Nevada residence, ethnicity, Hispanic/Latino origin, and their highest level of education. The design of the survey incorporated both closed and open-ended questions. The second part of the questionnaire asked the participants to share their experiences in receiving ABA services and the extent to which those services were received. The survey also included questions asking what cultural values (if any) were important to them in the process of receiving services. The survey instrument used is presented in Online Resource 1. Upon completing the survey, we asked participants if they wanted to be further contacted to participate in either a focus group or interview. The focus group would be an opportunity for families to further describe their experiences in a group setting, while the interview would be a 1:1 opportunity to discuss their experiences further. The method and results of the interviews and focus groups are described below under Study 2.

Coding and Data Analysis

We used Qualtrics as a software to obtain frequency counts for all selection-based questions (i.e., Likert-scale questions). To analyze the responses to the open-ended questions, the research team used qualitative methods to code responses according to themes and similar responses across participants. The first author and second author reviewed each response and created a general category based on each participant's response. For example, to the question, "Were there any barriers in receiving ABA services?" a participant responded with "Issues with insurance and cost of services." From this response, we created a theme and categorized it under "insurance/funding" for reporting purposes. When other participants responded similarly to this question (i.e., ABA agencies not accepting their insurance plan, not having sufficient funds to pay out of pocket), we placed it under the same category. Once the questions had been reviewed, we used a frequency count for similar codes using Google Sheets.

For other open-ended questions, we took a more in-depth process due to varying responses. These questions included the following: "When you started ABA services, how much did you know about ABA or about your child's diagnosis?"; "What are some cultural values that you hold that are important for your child's provider to know?" and "What did you find to be the most helpful/effective in receiving ABA services?" For these questions, the first and second author independently read the survey responses and created our own summary based on whether there were frequent responses to the questions or similarities across the responses. Finally, we met to discuss our own summaries and created an aggregate product to report from the findings.

Results

We include direct quotes from the participants throughout our results. For participants who responded in Spanish, we present the Spanish quotes first, followed by an English translation in brackets.

Table 2 contains a summary of the open-ended questions collected through the Participant Demographic and Experience Survey. Seven participants (36%) indicated that they had received ABA services for more than 3 years, and 11 participants (62%)

Table 2 Open-ended parent responses from online survey

	N	%		N	%
Length of ABA services			Parent values around services		
Less than 6 months	1	6	Treatment planning	6	33
6 months – 1 year	4	23	Individualized planning	3	17
1 year – 3 years	6	33	Data progress	3	17
More than 3 years	7	36	Involvement	5	28
Major initial barriers			Other	1	5
Waitlist	5	28	Learning about ABA services		
Insurance/funding	3	17	Internet search	2	12
COVID-19 pandemic	2	10	Resources	6	34
None	3	17	Family/friends	3	18
Other	5	28	Service provider	2	12
			Referral	3	18
			Walk-In	1	6

N = 18. "Other" major initial barriers identified were the lack of providers in the area (including providers that would accept child's age because they were older than 10) and lack of flexibility with the child's school schedule and doing ABA at the same time

indicated receiving services for less than 3 years. Across participants, the most common reported initial barriers to begin ABA services were an extended waitlist time, issues around insurance/funding, and the COVID-19 pandemic. Other barriers that parents indicated were the lack of providers providing therapy for their child's age and the lack of flexibility in scheduling to attend both school and ABA related services. Several participants ($n = 6$, 34%) reported learning about ABA services through community resources. When we asked parents what they valued around ABA services, they reported: treatment planning, individualized planning, data progress, and involvement. For example, one parent stated, "I like the planning of all his programs. They push him to do it even when he gets frustrated. He gets challenged, but I know he can do it."

Table 3 provides a summary of parents' experiences with ABA services. Overall, the majority ($n = 14$, 82%) of parents reported always feeling included around treatment planning, followed by 12% ($n = 2$) reporting that they often felt included. Similarly, the majority ($n = 9$, 53%) of parents reported ABA agencies were always taking cultural considerations around treatment planning, followed by 24% ($n = 4$) of parents reporting cultural considerations were considered often. However, one family (6%) rated "rarely" for agencies taking cultural considerations. Finally, the majority of parents ($n = 13$, 77%) reported either always or often having someone available to communicate their needs in Spanish if needed. In contrast, two parents (12%) reported "rarely" or "never" having someone available to communicate with them in Spanish.

For the remainder of the open-ended questions, we were unable to create repetitive themes around some of the responses due to the varying responses. However, there are implications from the collected results, which are outlined here. For example, in response to "When you started ABA services, how much did you know about

Table 3 Parent experiences around ABA services

Question	Always N (%)	Often N (%)	Sometimes N (%)	Rarely N (%)	Never N (%)
Do you feel included around treatment planning for your child?	14 (82)	2 (12)	1 (6)	0 (0)	0 (0)
Do you feel that ABA agencies took cultural considerations in treatment planning for your family?	9 (53)	4 (24)	3 (19)	1 (6)	0 (0)
Does your service provider speak Spanish or was there someone you could communicate your needs to?	9 (53)	4 (24)	2 (11)	1 (6)	1 (6)

N = 17

ABA or about your child's diagnosis?" – all families reported very minimal to no knowledge of what ABA services were or the effects it would bring to their family. One parent reported that they "Did not know all the benefits from ABA, and would have enrolled sooner if they had." In addition, another parent reported that because they "did not know much about their child's diagnosis, a lot of research had to be done on their own. In response to the next question – "What are some cultural values that you hold that are important for your child's provider to know?" – some parents identified some of the following values: trust, respect, open communication, personal cultural practices, and family.

Method Study 2: Structured Interviews and Focus Groups

Recruitment, Participants, Setting, and Materials

Once surveys were completed, we contacted families (with their preference of contact) that indicated an interest to participate in either an individual structured interview or in a focus group within a week to follow-up; thus, all participants for Study 2 were pooled from those who participated in Study 1. Based on the participants' availability and language preference, we organized two interviews to take place over the phone and two focus groups online. Offering the interviews and focus groups over the phone and online allowed participants across the state to participate and ensure appropriate safety precautions due to this study taking place during the COVID-19 pandemic.

Two Latino parents participated in the structured interviews. Seven Latino parents participated in two focus groups. Focus Group 1, conducted in English, included a married couple and an additional participant. Focus Group 2, conducted in Spanish, included four Latino parents as participants. The majority of parents were still currently receiving ABA services ($n = 5$, 56%), while the other participants had previously received services ($n = 4$, 44%). Aggregated participant demographics are presented in Table 4, including the parents' cultural identity, their primary language

Table 4 Sociodemographic characteristics of structured interviews and focus group participants

Characteristic	N	%	Characteristic	N	%
Gender			Hispanic/Latino origin		
Female	8	89	Mexican	8	100
Male	1	11	Education Level		
Age			Did not graduate	1	12.5
25–34	2	22	High school diploma/GED	4	50
35–44	7	78	Some college/Associate	2	24
County of NV residence			Technical degree	1	12.5
Clark	2	22			
Washoe	7	78			
Ethnicity					
Hispanic/Latino	9	100			
Language spoken in the home					
English	2	25			
Spanish	1	13			
Both equally	5	62			

N = 9. Only some demographic information was collected from the male parent (participant from the married couple) from the English-speaking group due to only the other parent completing the participation forms

spoken in the home, and parents' educational level. All participants reported Mexican being their cultural identity. Parents reported a range of responses for their primary language spoken in the home; ($n = 5$, 62%) of parents reported speaking English and Spanish, followed by primarily English ($n = 2$, 25%) and then Spanish ($n = 1$, 13%).

Procedures

All interviews and focus groups were conducted by the first author. As stated above, we conducted two separate interviews: one in English and one in Spanish. The one-on-one interviews were conducted for families who did not select to participate in a focus group and provided additional flexibility for families to discuss their experiences. The interview was structured similarly to the focus group (outlined below), including the purpose and general overview for the interview at the start. The semi structured interviews were conducted over the phone and lasted approximately 20 to 45 min.

We conducted two separate focus groups: one in English and one in Spanish. We conducted all focus groups online via the Zoom platform and each lasted approximately 90 min. At the beginning of each focus group, the moderator (first author) described the purpose and general overview of the focus group. Following the introduction, we introduced a group activity using The ACT Matrix (Polk & Schoendorff, 2014). The ACT Matrix is a tool used to track short-term and long-term outcomes of an individual's behavior and determine the behavior's function (see Polk & Schoendorff, 2014). The purpose of running The ACT Matrix was to identify parents' values and actions to take in order to move toward those values (i.e., spending quality time together).

At the start of the activity, we discussed the difference between values and goals with a guided example. This distinction is important to demonstrate how values are never ending and goals are achievable. The example was further demonstrated with the presentation of a blank ACT Matrix. We explained each of the ACT Matrix quadrants, as well as demonstrating how the discussed example (value around health) would fit in each quadrant area. Next, in a discussion format, we asked the group: "What are things you value/are important to you?" We waited to obtain responses from the majority of participants and allowed for the group discussions to occur. We guided the group around the different areas of the matrix and moderated the group in order to allow all participants to share their experiences. During this activity, several values were identified by the group that helped with further discussion during the session. At the end, we provided parents with a copy of a blank matrix to complete independently and track their own changes for future use.

At the conclusion of the focus groups, we provided participants with additional resources for support groups and parent training opportunities in the state. In addition, participants were encouraged to further contact the moderator/researchers if they had additional questions or comments that were not addressed in the group context. A separate researcher scored a treatment fidelity checklist to ensure the moderator included the same guiding questions and protocol for both focus groups. Treatment fidelity was scored at 100% across both focus groups.

Coding, Data Analysis, and Interrater Reliability

We used qualitative research methods to code and analyze the responses from the structured interviews and focus groups. Qualitative research is a "systematic approach to understanding qualities, or the essential nature, of a phenomenon within a particular context" (Brantlinger et al., 2005, p. 195). Qualitative methods are empirical, involve observation and experience, and enable us to address complex issues of practice including working with diverse individuals. In addition, qualitative methods can be useful during the pre-intervention stages to gather perspectives from the population and examine the acceptability of an intervention (Hitchcock et al., 2010). The outcomes of qualitative research can inform practices to provide a detailed description of a given problem. Qualitative methods can be conceptualized as a systematic descriptive assessment of social validity. In this study, we evaluated the social validity of ABA from the perspective of Latino families using three coding cycles (see, Saldaña, 2021 for more detail).

We audio recorded all focus groups and interviews. We used a transcription company to produce the initial transcription, then manually compared the transcription to the audio recording to ensure it was correct. Additionally, we edited some words from the initial transcriptions that did not translate appropriately (e.g., use of slang terms, 'Spanglish', or acronyms). In addition, a separate researcher listened to and verified the transcription from the Spanish-speaking focus group to ensure the context was transcribed appropriately. We proceeded to the coding process using the three cycles of coding as outlined by Saldaña (2021). The overall goal of the cycles of coding was to identify themes in the participants' discussions that related to cultural values and barriers that were faced by the participants in the context of receiving ABA services for their children with ASD. For the first cycle of coding, elemental coding methods were utilized. Elemental coding methods are "primary approaches to qualitative data analysis" (Saldaña, 2021, p. 129). The form of elemental coding that we used was in vivo coding. The in vivo method is a form of qualitative data analysis that places emphasis on the actual spoken words of the participants (Manning, 2017; Saldaña, 2021). In addition, in vivo coding can be helpful when researchers are interacting with participants from a particular culture and better understand stories or phrases used throughout (Manning, 2017; Manning & Kunkel, 2014). The first cycle involved listening to and reading the focus group transcripts to review the overall content. This initial process allowed us to become familiar with the collected data. As we listened to the audio recordings, we took notes and began to highlight important areas of the participant's experiences. Next, as suggested by Creswell (2007), two researchers individually read and manually coded the transcripts. This first cycle allowed for researchers to get familiarized with the content and apply initial codes to the relevant areas. We utilized in vivo coding methods in order to best capture the meaning of participants' experiences and identify open codes.

The second cycle of coding involved focused coding. Focused coding searches for the most frequent or significant codes from in vivo coding to develop salient categories in the data and "requires decisions about which initial codes make the most analytic sense" (Charmaz, 2014, p. 138). The aim of focused coding is to connect statements and experiences across all of the participants' responses. Next, as Creswell (2007) recommended, each researcher independently coded and created separate themes. Once this was complete, all researchers met to discuss the themes and categories they had created. Furthermore, they agreed/disagreed on themes and categories that would be presented and further analyzed (Creswell, 2007). The researchers discussed all areas of disagreement on themes and categories and reached a consensus on which themes and categories to use for the remainder of the coding process. Upon agreement, the themes were discussed to increase reliability and improve the validity and credibility of the data as a whole and what codes would meet the criteria. In addition, a third researcher coded the data without seeing the themes that had been finalized. This allowed for further reliability to decrease possible researcher bias and make sure no further themes had been missed (Luker, 2008).

The third and final cycle of coding used was codeweaving. Codeweaving is "the actual integration of key code words and phrases into a narrative form to see how the puzzle pieces fit" (Saldaña, 2021, p. 345). Part of the final codeweaving process was to jointly review the significant overlap in themes into comprehensive categories. The list of themes was ultimately jointly reviewed by all the researchers. This collaboration helped to clarify and refine the specific themes. The number of codes were not specifically counted for reliability as "counting conveys a quantitative orientation of magnitude and frequency contrary to qualitative research" (Creswell,

Table 5 Themes and subcategories for all focus groups and structured interviews

Theme	Subcategories
Family and cultural values	Family
	Trust and friendliness in therapeutic relationships
	Role as a parent
Reaction to receiving a diagnosis	Perspectives/knowledge of receiving a diagnosis
	Lack of support
Impact of ABA services	Positive outcomes
The future of ABA and recommendations	Transitional services (aging out)
	Need for resources and further education

2013, p. 185). Instead, reliability in the coding process was achieved through the process of ongoing discussion and consensus among the three researchers.

Results

The overall goal of this qualitative approach to coding the participants' discussions was to identify themes within and across their responses that can then provide information to help practitioners move toward culturally responsive service provision for Latino families. Therefore, we present the results in terms of themes and subcategories identified within and across their responses. Similar to the above, we include direct quotes from the participants to illustrate the themes and subcategories that we identified during the coding process. As we present the results, the Spanish quotes are provided first in italics, followed by the English translation in brackets.

While we identified some themes that were more frequently discussed in one focus group than the other (and vice versa), we identified consistent themes and categories across both focus groups and the structured interviews. We identified four main themes that emerged across the focus groups and structured interviews, which are outlined in Table 5. These themes included (1) family and cultural values; (2) reaction to receiving a diagnosis; (3) impact of ABA services; and (4) the future of ABA and recommendations. Each theme comprised two to three subcategories. For each theme, we describe the characteristics of the parents' responses, followed by illustrative quotes. We provide additional illustrative quotes for each theme in Online Resources (2–6).

Family and Cultural Values

Family

Several parents described the importance of family (familismo) across different lenses. First, parents described the importance of family as doing the best they could for their child. For instance, to ensure their children have the appropriate support system to be successful in the future, as well as to support everyone else in the household. For example, at the start of the English-speaking focus group an overarching value that a parent reported and others agreed on was for their “kids to do well in life.” Parents expressed the different ways this looked in their household. For instance, one parent described the importance of communication and flexibility that needed to happen in their household, “I’ll just work, you know, cleaning jobs, fast food jobs, whatever it is just so that the schedule is flexible for therapies-pick up drop-offs whatever it needed to be like. I was a hundred percent and I still am a hundred percent dedicated to whatever my boys need, that always comes first. So, it just took a lot of communication between my husband and I to decide that factor.”

Trust and Friendliness in Therapeutic Relationships

Similarly aligning with the literature, the value of confianza (trust) and personalismo (friendliness) were discussed (Magaña, 2020). With some families having their children enrolled in 20–35 hrs of ABA therapy, many are left with faith and trust that their child is getting the best treatment and care possible. One parent stated, “Sometimes they [children] cry at drop off, sometimes they don’t and then you’re wondering. I think what helps with the parent classes is being able to see how my kids interact with the therapists.” Another parent discussed the importance of trust with their service provider, “I wanted there to be honesty of what was going on with my child’s progress, so I could really know how well or not well he was doing.”

Due to parents having little information about ASD when they first started ABA therapy, building therapeutic and open communication relationships with their child’s therapists was important. One parent agreed that she always felt comfortable sharing her concerns with maladaptive behaviors she was seeing in the home, “They let you know when you bring up these issues. They’re like this is normal, this is what we’re seeing here, this is what we’re going to work on or this is how we’re going to track this and that I need. You don’t feel crazy when you’re around them.” Not only does building a therapeutic relationship help families gain trust with services, but it may also help providers have better communication with families.

Role as a Parent

Another clear value that was present was their active and engaging role as a parent. Across the different stages of raising their children, parents were often questioning if they were doing enough or the right thing (e.g., decisions regarding treatment, engaging with other family members). One parent from the Spanish-speaking focus group stated *“Yo me sentía muy mal. Yo creía que yo era la responsable de muchas cosas que le pasaban a mi hijo, porque no le enseñé a defenderse. Pero yo siento que en el momento hacemos lo que sentimos, qué es lo mejor para ellos y nuestro instinto de mamá.”* [I felt really bad. I thought that I was responsible for many things that happened to my son because I did not show him how to stand up for himself. But I feel that in the moment we do what we feel is best for them and trust our motherly instinct]. See Online Resource 2 for additional illustrative quotes.

Reaction to Receiving a Diagnosis

Perspectives/Knowledge of Receiving a Diagnosis

A commonality across many of the participants was their shared experience of when their child was first diagnosed with autism. Several parents described how they were initially ignorant of what autism was, and even in denial that their child had autism. One mother stated, "*"Al principio cuando me dijeron que mi hijo tenia autismo, a ratos se le va a ir; vino la ignorancia de uno como Latino. Yo creo, que la comunidad Latina es muy ignorante en ese aspecto, deberíamos estar más educados.*" [At first when I was told my son had autism, I thought it'd go away; here came the ignorance of one as a Latino came. I believe that the Latino community is very ignorant in this respect, we should be more educated [about autism].

Other parents were not prepared to receive the information that their child has autism. Families discussed that receiving an ASD diagnosis was stressful for their family and they needed time to emotionally adapt. A parent from the English-speaking focus group stated, "For me the diagnosis was a traumatic experience. I wish we were guided by some type of family counselor. At that point, I could not handle it."

Lack of Support

The term "stigma" was never utilized by either the moderator or parents during the discussion; however, the context of stigma was related to a lack of support from the community/service providers and isolation from family members. As mentioned earlier, while participants identified "family" as a value, the effects of the lack of support they had received from extended family members was emphasized as well, "*Yo en lo personal me alejé de mis amistades y de mi propia familia por pensar que van a juzgar, van a criticar, y no entender la condición de mi hijo*." [Personally, I distanced myself from my friends and my own family because I thought they would judge, criticize, and not understand my son's condition]. Several participants described struggling to maintain strong family relationships and overall feeling isolated, "Outside family doesn't understand what it is like to have our kids, they don't know what our daily struggles or challenges are. As much as they want to be supportive, they just don't get it." See Online Resource 3 for additional illustrative quotes.

Impact of ABA Services

Positive Outcomes

All parents ($n=9$) reported positive impacts from receiving ABA services. Some areas of importance included teaching daily living skills, independence skills, and developmental skills. One parent from the structured interview stated, "He's not head banging as much and he's learning to say words. I remember crying just because he learned to say 'eat.' They are little milestones!" Another parent from the Spanish-speaking focus group shared a similar positive outcome for her child, *"Ha pasado muchas horas en terapia [ABA], pero pienso que pues sí le ha ayudado mucho porque ahora come, come comida. Creo que a los 4 años empezó a comer chicken nuggets. A los cuatro años que empezamos me dio un beso porque no daba besos, no hacía nada. Sólo pasaba metido debajo de la cama y en el closet."* [He has been through many hours of therapy [ABA], but I think it has helped him a lot because now he eats food. I think at 4 years old he started eating chicken nuggets. At 4 years old when we started [therapy] he gave me a kiss; he did not kiss, he did not do anything. He would only hide under his bed and in the closet].

Other effects were improvements in quality of life for both parents and children due to ABA services. The activity presented at the beginning for the focus groups provided guidance for families to identify what they valued for both themselves and their families. A parent from the English-speaking focus group stated, "The behavioral team went out to different locations and I thought that was really life changing for my family because now we can go to restaurants, we can go to the grocery store, and we do a lot better with meltdowns at those different places. Because it was not possible to walk into Walmart and my child would start screaming at the top of her lungs for reasons I don't know and so now we can…life is better."

Barriers

The time from the initial ASD diagnosis to the time of receiving services varies from each family and can depend on several external factors to start services; for instance, the number of providers in the area, insurance/funding that are in network with providers, and whether providers have the capacity with staff to provide services to an incoming family. As mentioned above, while parents saw the impact of ABA services, a barrier that many families discussed was the initial wait for services to become available. One parent stated, "The wait list was very scary because although they told me I was going to get help, I sat there alone for 8 months before I got it." Similarly, another parent agreed on the difficulties of being on a waiting list, "First, the waitlist was a big barrier. I wish there would have been something available to start with while we waited for services."

Language Barrier

A significant difference and added subcategory that emerged from the focus group conducted in Spanish, was the presence of a language barrier in order to receive an ASD diagnosis and ultimately ABA services. One parent stated, "*Ha sido un poco difícil en parte, porque también como latina no hablo mucho inglés*." [It has been a little difficult in part, because as a Latina, I do not speak English]. Similarly, another parent stated, "*Pero si era muy difícil encontrar quien hablara español, pues yo como podía yo les decía mi hijo necesitaba servicios y así fue como que a ellos me refirieron a los servicios de ABA*." [It was very difficult to find someone who spoke Spanish. As I could, I told them my son needed services and that's how they referred me to ABA services]. For another parent, communication was similarly a present barrier to being involved once services were attained, "*No creo que me sentía muy incluida por ser parte de esas conversaciones para estar involucrada [planificación del tratamiento], sin embargo, pero sentía la necesidad de involucrarme. No hablo muy bien el inglés, pero lo entiendo bien. Así que solo miraba en casa cómo trabajaban con mi hijo y luego hacía lo mismo*." [I don't think I felt very included to be part of those conversations to be involved (regarding treatment planning), however I still felt the need to involve myself. I do not speak very good English, but I understand it well. So, I would just watch at home how they worked with my son and then did the same thing]. This barrier was less evident from the English-speaking group. See Online Resource 4 for additional illustrative quotes.

The Future of ABA and Recommendations

The Need for Resources and Further Education

Across both focus groups and interviews, the greatest area of need reported by parents was the importance of providing learning opportunities about ASD and ABA. While some parents had heard about the positives and negatives of ABA prior to starting services, they really did not know what ABA therapy was and why it would be the best fit for their child. One parent stated, "Both therapists [from early interventions] brought up ABA early on and at first I didn't know if it was something I was comfortable with. Yeah, it was just something that I didn't know. Because there was so much hearsay that it's like basically you're putting your kids in this program to shut off all his emotions or to tell him that his stims (stimming/self-stimulatory behaviors) are not okay." Others had expressed wanting to receive more training on the techniques and explaining the rationale behind the behavioral strategies, "I had to watch without understanding, so that can definitely be changed with more understanding and education."

In both focus groups, parents offered recommendations for providers to consider, especially with families who are newly diagnosed with ASD. One parent stated, "*Necesitamos un entendimiento de lo que es ABA para nuestra comunidad y yo creo que es importante para los papás que vienen en este nuevo ciclo a los que están recientemente siendo diagnosticados, que hubiera un manual o algo en una introducción mejor.*" [We need a better understanding of what ABA is for our community and I believe is important for parents who come into this new cycle of being recently diagnosed, there should be a manual or something for a better introduction].

Transitional Services (Aging out)

A concern/worry that was brought up during the English-speaking focus group was the availability of services after their children turn 18 years old. Many parents were already aware that in their area there are little to no services available for adults with ASD, "There's so much for the little babies and there's nothing for you know, those little babies. They grow up of course and there's no continuation. We're parents, we're not going to be here forever. There's going be times when our children are here without us and there's just such a lack of services for that point. It's just really scary." While many ABA organizations do not provide services after children turn 18 years old, a common process is working on individualized skills to prepare them for their next phase of life (i.e., job searching, independent living). While there is still much work to be done in this area and creating these services, further support is also needed for parents to navigate the continuation of services. See Online Resource 5 for additional illustrative quotes.

Discussion

The aim of this study was to identify and learn about the cultural values and beliefs held by Latino families in Nevada. In addition, we also examined barriers faced by Latino families when accessing ABA services. In Study 1, we distributed the Participant Demographic and Experience Survey to Latino families who were currently receiving ABA services or had received services in the past. The survey included questions about the families' cultural identity, their primary language spoken in the home, and parent educational level. The second part of the questionnaire asked the parents to share their experiences in receiving ABA services and the extent to which those services were received. In Study 2, we conducted structured interviews and focus groups with some of the families who participated in Study 1. From the structured interviews and focus groups, we identified four main themes: (1) family and cultural values; (2) reaction to receiving a diagnosis; (3) impact of ABA services (4) future recommendations for the field of ABA. From these themes, we found what aspects were meaningful in receiving ABA services, as well as barriers that families faced when seeking services.

An initial barrier that 28% of families reported was being on an extended waitlist for services. Similarly, a survey conducted as part of the Nevada Legislative Counsel Bureau Audit Division (2021) found that waitlist issues were the most frequently mentioned barrier. They found that 55% of providers had a 4-month waitlist for their practice and 18% had a waitlist of over a year. It is estimated that for Nevada in 2020, there were only enough providers to serve about two out of every three children who needed ABA services (Legislative Counsel Bureau Audit Division, 2021). While the number of ABA providers in Nevada has significantly increased, it is still insufficient to meet the needs of children who need services. The wait time to receive treatment is even longer for low income households in comparison to families with private insurance (Legislative Counsel Bureau Audit Division, 2021). While extended time on a waitlist is a common barrier for Latino families (Magaña, 2020; Rosales et al., 2021), ways behavior analysts can address this are limited in the literature.

An interesting aspect worth noting from both studies were implications regarding language and barriers around language. First, when analyzing the data completed from the English and Spanish forms. In general, we found no differences in some of the general demographic data. However, there were meaningful differences to the following question, "What is your primary language spoken at home?" From the participants who completed the form in Spanish, 60% reported primarily speaking Spanish in the home, while no participants who completed the form in English reported Spanish being the primary language spoken in the home. These data demonstrate how much language matters. When given the option between Spanish and English, the families that primarily speak Spanish in the home, chose to complete the study in Spanish. This lends support to the assertion that given the option of having a part of services and information being available in Spanish is important to families.

As discussed in the literature review, language barriers play a critical role in developing and maintaining a good therapeutic relationship between families and providers (Ferguson & Candib, 2002). A difference that emerged between the focus group conducted in Spanish in comparison to the focus group conducted in English, was the presence of a language barrier when seeking services. This can be a call for service providers to ensure their services are modified to meet the needs of the Latino community. For example, ensuring paperwork and communication is in a language that families will completely understand. For instance, having onboarding paperwork, behavioral support plans, and trainings be available in their language of preference.

This feedback aligns with the subsection of the current Ethics Code for Behavior Analysts (BACB, 2020) under Sect. 2.08 Communicating about Services:

> 2.08 Behavior analysts use understandable language in, and ensure comprehension of, all communications with clients, stakeholders, supervisees, trainees, and research participants.

Across both focus groups and interviews, the greatest area of need reported by parents was the importance of providing learning opportunities about ASD and ABA services. In another of our open-ended questions in Study 1, 34% of families reported learning about ABA services through community resources. This number could be a good indicator as to where and how service providers can disseminate general information about services. As noted in the results of Study 2, several families indicated an overall lack of knowledge about ASD and how to attain information about ABA services. The findings of Latino families having limited knowledge about ASD are consistent with the literature (Chlebowski et al., 2020; Zuckerman et al., 2014). However, to our knowledge, available information for Latino families about their awareness in ABA related services is limited in comparison to Latino's knowledge about ASD in general.

Families in this study reported that even when they started ABA services, they still had several questions about ABA (i.e., the evidence support) and wished they had more knowledge about their child's ASD diagnosis. One recommendation offered by parents in the English-speaking group was for service providers to give families more information about the time commitment needed for ABA services. One way service providers can increase parent knowledge on ABA is to provide ongoing training opportunities on specific topic areas that are applicable to their children. For example, during parent training sessions the importance of reinforcement strategies can be discussed, followed by an application of reinforcement strategies for their child. In addition, collaborations with outside community agencies would be beneficial to create an easier referral process for families or another resource for information on the topic of ASD and ABA. For instance, collaboration events can include practitioners from the community providing general information and answering questions families may have. In addition, this would also help build a trusting relationship between families and service providers from the initial start of services.

Overall, families responded positively to being included in treatment planning for their child. While the majority of families reported ABA agencies always taking cultural considerations around treatment planning, some families indicated that ABA agencies sometimes or never took cultural considerations in treatment planning, respectively. This question was asked on a Likert-type scale and did not allow participants to add follow up with additional information. While "cultural considerations" were not defined for participants, it is still an indication that there are still ways behavior analysts should be mindful and open to learning about a family's cultural values and practices. For families who did respond that culture was considered, a further follow up would aid the analyses of what exact considerations were taken from providers. For example, examining if families were given the opportunity to select goals that are culturally relevant (e.g., mealtime prayer).

A strength from the interviews and focus groups were the inclusion of different experiences from families that had gone through the process of receiving ABA services. For instance, participants were able to share a range of experiences due to the large spectrum of their children's ages and duration of experience with ABA. The participants had children ages 0–6 years old ($n=3$), 6–15 years old ($n=2$), and 16–18 years old ($n=3$). This also allowed the focus groups to serve as a support network for families who were in their first year of services, while others were looking for support to transition services once their children turned 18 years old. The themes that were created from the results demonstrated the importance of those topics across groups, as each family offered different viewpoints.

In general, the discussion of values aligned very similarly with the literature reviewed above, specifically with the values of familismo (familism) and personalismo (interpersonal relationships). Although, the presentation of these values was somewhat different. In the literature, the value of familismo is typically focused on the engagement and inclusion of extended family members during treatment planning. For our participants, the value of familismo was centered more toward the well-being of their child and the role of the nuclear family members in the household to be supportive as a unit. For instance, goals were centered for their child to gain independence and be part of the community. In addition, families discussed the changes and sacrifices that had to be made for their family in order to integrate ABA services into their lives. Our results suggest an emphasis on persistence and grit from their family values to reach those goals. This included working additional jobs to support their family and maintaining jobs that offered flexibility for their children's schedule. On the other hand, familismo was also discussed as a value that was there for their nuclear family, but was not demonstrated from their extended family. Participants discussed how their relationships with family members had negatively shifted and the difficulties they faced from the family's lack of understanding what their child needed.

Our results also expand on current knowledge about the decision-making roles Latino families, particularly the roles that Latino mothers, take during this experience. Across both focus groups, all but one participant was a mother of a child with ASD. The one participant that identified as male, was part of a dyad couple;

no fathers of children with ASD participated on their own. A challenge that mothers expressed was feeling that they had to make the "right" decision of care for their child. Many of the mothers discussed the constant questioning of whether they were doing the right thing in having their kids in ABA services and the unknown if they were doing the best that they could. For one parent, her decision was not clear for her until years later. However, whether to begin services or not was only the start for some families taking the best care of action for their child with ASD. Parents often struggled with their own personal thoughts, questioning if they were doing enough for their children and related it back to questioning if they were a good enough parent. This is not a unique aspect for Latino families, but it is an important issue that needs to be addressed. While not discussed in depth in this study, the cultural construct of gender roles can be prevalent in the Latino community. This value also extended to their other children in the home. Parents often recognized that much more of their time was spent on their child with ASD, in comparison to their other children.

Understanding how these cultural values impact ABA services may help service providers foster a better therapeutic relationship that can ultimately lead to better service outcomes. For example, promoting values such as personalismo (interpersonal relationships) can facilitate conversations, in which expectations for services and treatment can be discussed (Chlebowski et al., 2020; Hackethal et al., 2013). In the context of bringing the value of personalismo to families during the focus group session, the researcher initiated separate conversations and ensured confidentiality for families to feel more comfortable. While the researcher had limited rapport built with participants, service providers can ensure the value of personalismo continues to build across meetings or sessions. Furthermore, creating an interpersonal relationship and discussing treatment expectations can often be built into cultural adaptation frameworks (Domenech Rodríguez et al., 2011). Thus, cultural values are a vital component when adapting treatment services, specifically when making modifications to parent training programs.

There are some limitations from the study that should be noted. First, the sample size is small, especially given the total Latino population in Nevada (29.2%; $n=918{,}045$; US Census Bureau, 2021). As such, the data collected from this small sample is likely not representative of the total population of Latino families receiving services in the state of Nevada. The extent to which our study is representative of Latino families within the state is that participants in this study resided within two of Nevada's 16 counties, Washoe and Clark County (72% and 28% respectively). Both of these counties are the largest metropolitan areas in Nevada. Participation from other rural counties would provide more insightful information due to rural populations being less diverse, both racially and ethnically. Future research can investigate and compare the needs of Latino families living in rural Nevada to Latino families receiving services in larger metropolitan areas. Similarly, the diversity of families that participated in the study was limited with 89% of participants identified as Mexican as their Hispanic/Latino origin. As discussed previously, there are several subgroups within the Latino population and values can vary across each group. Future research can investigate other regions of the country and compare their experiences receiving ABA services.

Another limitation was the accessibility and distribution of the survey. Due to recruitment taking place during the COVID-19 pandemic, recruitment and dissemination of the study primarily took place online. While we shared recruitment flyers with ABA providers who were currently working with Latino families and posted on ASD community websites, we were still unable to yield a higher representative sample. Future studies may expand recruitment strategies by sharing at community events in Latino communities. A final limitation of the study was not including a question in the survey regarding how many years families had lived in the US. Responses to this question may provide better information as to whether these perspectives and values align with a specific generation for Latino families or if values mentioned came from across generations. The number of years living in the US may also be correlated with their knowledge about ASD and accessibility for services (Rosales et al., 2021). Future research may include adding a question on how many years they have lived in the US and/or how many generations their family has lived in the US (e.g., first generation, second generation).

The results of Study 1 and Study 2 provide some implications for future research to address the needs of Latino families receiving ASD services. While research in the field is starting to explore ABA service delivery to Latino families with children with ASD (see Rosales et al., 2021), there is still limited research focused on experiences with Latino families receiving ABA services and how to culturally adapt treatments. Findings from this study can help further identify the different contexts and methods that can be adapted for a given community. The data from this study also suggest that there is still work that needs to be done from a service provider's standpoint. For example, even when Latino families receive ABA services there are still questions regarding the purpose of treatment procedures and knowledge of other resources. Behavior analysts should continue to work on learning about different family cultures and practice cultural humility across all families that they serve.

In summary, we were able to identify important cultural values for a small sample of Latino families receiving services for ASD and other related developmental disabilities. In addition, findings from this study provided an opportunity for families to share their experiences about receiving ABA services. Overall, families responded positively with the services they received; however, there is still much work to be done in order to provide high quality ABA services to Latino families with children with ASD. This study offers support to what cultural values are important to the Latino community in Nevada and can be used to culturally adapt interventions.

Supplementary Information The online version contains supplementary material available at https://doi.org/10.1007/s42822-022-00115-0.

Data Availability The datasets generated during and/or analyzed during the current study are available from the corresponding author on reasonable request.

Declarations

Ethics Approval This study was performed in line with the principles of the Declaration of Helsinki. Approval was granted by the University of Nevada, Reno's Institutional Review Board, protocol#1690679–2.

Consent to Participate Informed consent was obtained from all individual participants included in the study.

Consent for Publication Participants signed informed consent regarding publishing their data.

Conflict of Interest The authors have no relevant financial or non-financial interests to disclose.

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