




A First Look at Applied Behavior Analysis Service Delivery to Latino American Families Raising a Child With Autism Spectrum Disorder

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Abstract

Recent statistics indicate children of Latino background are diagnosed with autism spectrum disorder (ASD) at a much later age than their non-Latino White counterparts. Once a diagnosis is made, it is critically important that families get access to evidence-based interventions, including applied behavior analysis (ABA) services. However, disadvantaging factors such as a lack of awareness of available services, poor health care access and health literacy, and language barriers may impact these families' ability to access and maintain ABA services. The purpose of this pilot study was to obtain preliminary information on the experiences of accessing and maintaining ABA services for a sample of Latino American families living in Massachusetts. We conducted structured interviews with 28 families that had a child with ASD aged 8 years or younger. Questions in the interview were related to the background and diagnostic experiences of the child; difficulties in accessing ABA services; and for those children receiving ABA services, parents' perceptions of the services. Results of the interviews are summarized, and implications for future research and service delivery are discussed.

Keywords autism spectrum disorder · Latino American families · ABA service delivery · cultural variables

Although autism spectrum disorder (ASD) is prevalent among all races, ethnicities, and socioeconomic populations, prior research has consistently shown that Black children and children from Latino¹ backgrounds are diagnosed with ASD less often and at a much later age when compared to their non-Latino White counterparts (Durkin et al., 2017; Mandell et al., 2009; Wiggins et al., 2019). Research findings have also identified significant health disparities for Latino American children in the United States relative to children of other racial/ethnic groups. For example, Flores and Tomany-Korman (2008) conducted the National Survey of Children's Health with a representative sample of parents and guardians of

102,353 children. The results indicated that children of Latino descent were more likely to lack medical insurance (21%) compared to Native American (17%) and African American (7%) children. The authors also found that, compared to children of other racial/ethnic groups, Latino children were more likely to be in poor or fair health, less likely to have a usual source of medical care, and more likely to experience problems receiving specialty services. Likewise, these authors reported that Latino children were less likely to make regular visits to a physician when compared to non-Latino White and African American children.

Another important and related health consideration for Latino American families is that approximately 60% speak a language other than English at home (Flores & Tomany-Korman, 2008). This presents a unique challenge in accessing health care. For example, Zuckerman et al. (2013) reported a low percentage of pediatricians in California (the state with the largest Latino population in the United States) offered general developmental screenings in Spanish. In addition, they found that more than half of the pediatricians reported language differences between themselves and their patients as a frequent barrier to ASD care for Latino children. These same pediatricians also reported that parents of Latino children who spoke Spanish as their primary language were less knowledgeable about ASD than parents of non-Latino White and

¹ The authors appreciate the importance of the term "Latinx" as a nonbinary version of Latino/a. Spanish is a gendered language, and the term "Latinx" is not widely known or adopted in all of the communities it serves to represent. For this reason, we elected to use the term "Latino" throughout the article.

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African American children. Similarly, Iland et al. (2012) found that Latina mothers of children with ASD commonly reported low competency in English as a barrier to obtaining care for their children, including obtaining a diagnosis and securing services and supports. The greatest area of need reported by parents was information about ASD supports and services and information to manage the child's behavior.

The challenges faced by all parents of children with ASD may be more pronounced for Latino families (Bishop-Fitzpatrick & Kind, 2017) by virtue of limitations in health care access and health literacy, as well as language barriers. Magaña et al. (2013) interviewed parents of 48 Latino and 56 non-Latino White children diagnosed with ASD to examine differences in diagnosis and treatment services. They found that Latino children were diagnosed almost one year later than non-Latino White children, received fewer "specialty services," and had greater unmet service needs. Given the evidence of disparities and barriers to health services for Latino families that have a child (or multiple children) with ASD, further investigation of the factors that create difficulties and/or impede access to services for this population is warranted.

Environmental, sociocultural, behavioral, and/or biological factors all exert influence on health and health system quality, including access and delivery of high-quality care (Bishop-Fitzpatrick & Kind, 2017). There is currently limited information on how these factors may or may not impact families of Latino American background before and after they receive applied behavior analysis (ABA) services for their child. Given the documented evidence of the effectiveness of ABA-informed interventions, it is of critical importance that all families are aware of and have equal access to these services. It is also important to evaluate families' perceptions of the ABA services received as a measure of social validity. Thus, the aim of the present pilot study was to begin to explore the factors that may impact the ability of Latino families that have a child with ASD to receive or maintain access to ABA services, as well as their perceptions of these services. Specifically, this research was designed to explore parents' experiences in (a) receiving an ASD diagnosis, (b) gaining access to ABA services, and (d) receiving ABA services for their children and their perceptions of these services. A pilot study of this nature has important implications for the broader Latino community because it can reveal both positive outcomes and specific areas of need that could be directly addressed by professionals working with this population.

Method

Interview

A structured interview with a script for trained interviewers was developed for the purpose of this study. The interview

items were informed by prior research on access to diagnosis and treatment services for Latino children with ASD (Magaña et al., 2013), and the structured interview was fully developed in consultation with a researcher who has experience in survey and interview development methodology, as well as experience in research in ASD (Carol Curtin). The interview contained questions related to the diagnostic process (e.g., at what age the family suspected atypical development in their child, the pediatrician's initial response to the parent's concern); the services the child currently received (e.g., speech therapy, occupational therapy, physical therapy, ABA services); reasons for not receiving ABA services (if applicable); the age when the child started to receive ABA services (if applicable); the location, quantity, and perceived quality of the ABA services received (if applicable); and sociodemographic data (i.e., education, race, ethnicity, etc.). The questions were closed ended such that participants were offered response choices such as responding yes/no, choosing from among answer choices, or reporting a number (e.g., the age at which their child received a diagnosis). This format ensured that the data would be quantitative in nature. A structured interview was chosen over a written questionnaire to provide parents with the opportunity to ask clarifying questions about the survey items.

Once the interview was developed, it was translated into Spanish by a native speaker (Rocio Rosales) and back translated into English for verification of accurate translation and approval by the university's institutional review board. The interview was piloted with two parents of Latino descent who have a child with ASD to ascertain the comprehensibility and relevance of the instrument and to ensure that important questions were included.

Participants in the study were interviewed by the first author or a secondary trained native Spanish-speaking interviewer. Interviewers followed the script during all structured interviews. Following the script helped ensure the interviews were conducted similarly across all participants. Prior to the start of data collection for the study, mock interviews were conducted among the research team to provide an opportunity for the interviewers to practice the structured interview script in its entirety in both English and Spanish. The interviewers practiced the script several times before the first scheduled interview and kept the script with them at all times. Interviews were conducted in Spanish or English, according to participant preference.

Participants and Setting

Parents were required to meet the following inclusion criteria for participation: (a) be 18 years old or older at the time of the interview; (b) be of Latino descent; (c) have at least one child 8 years old or younger with a diagnosis of ASD living in the home; and (d) have at least one parent in the household who

spoke Spanish for dual-parent households (bilingual parents were not excluded from the study).

Twenty-eight families were recruited from communities in Massachusetts through various mechanisms:

1. Emails with a flyer were sent out to a variety of community organizations and clinics that provide early intervention services to children with ASD.
2. Flyers in English and Spanish were posted throughout the community (e.g., at local libraries, laundromats, pediatrician offices).
3. Ads were placed in local Spanish newspapers.
4. Ads were placed with local Spanish-speaking radio stations.

Parents were also provided with a paper copy of the flyer at the conclusion of each interview and encouraged to share information about the study with families that met the inclusion criteria.

When a parent contacted the first author via email or phone, a screening was conducted over the phone to ensure the families met the inclusion criteria. If all criteria were met, an appointment was scheduled at the participant's convenience. Participants had the option to meet within their homes or in a public location, but all opted for a home interview. The interviewer scheduled 1 hr for all sessions, and all interviews were completed within the designated time. We required only one parent to be present for the interview and recorded one response on the interview form. In some instances, both parents were present, but this did not change the structure of the interview. That is, only one response was recorded. Families received a \$30 gift card at the conclusion of the interview in appreciation for their participation. The researchers also provided all participants with a packet of resources including listings for local ABA providers, parent support groups, and advocacy groups at the conclusion of the interview.

Data Analysis and Interrater Reliability

Two interviewers were present for all the interviews, which were audio recorded, in order to score participant responses using paper and pencil on the structured interview form. The audio recordings served as a backup in the event of a disagreement scored or if a question was not marked on the paper document during the interview. Scoring was compared between the two interviewers, and 100% reliability was achieved for all interviews. Results of the paper-and-pencil interviews were scored and subsequently managed using REDCap, a secure, web-based electronic research data-capture tool hosted at the University of Massachusetts Medical School (Harris et al., 2009; Harris et al., 2019). Two independent recorders scored the primary interviewer's scored responses from the

structured interview using REDCap's Double Data Entry module. The two records were compared using REDCap's Data Comparison Tool, an agreement for each response was determined by the first author, and a merged (final) record was created in REDCap for analysis. Data were summarized using a frequency count, and percentages were calculated for each response.

Results

Twenty-eight parents participated in the study. The large majority (71%) of interviews were conducted in Spanish, according to each participant's preference. Participant demographics are presented in Table 1, including the parents' and children's ages at the time of the interview, each parent's cultural identity, the parents' level of education, the number of years they had lived in the United States, the primary language spoken in the home and to the child, and responses to questions related to their socioeconomic status. Although we did not specifically ask families to report their income levels, we inquired as to whether they were receiving fuel assistance and/or food stamps as a proxy for this variable. Almost half of the parents we interviewed reported that their cultural identity was Dominican (46% of mothers, 43% of fathers). Another third reported they were of Puerto Rican descent (36% of mothers, 32% of fathers). A smaller percentage of families reported their cultural identity was Central American (11%) or South American (7%), and 7% of fathers included in this analysis were non-Hispanic. More than half of the parents we interviewed reported they had completed at least some college or earned a bachelor's degree (60% of mothers, 54% of fathers), and 61% of the families reported they had lived in the United States for over 10 years at the time of the interview. A significant percentage (68%) of families reported they spoke Spanish at home, whereas roughly a third (39%) reported they spoke exclusively in Spanish to their child with ASD. Finally, most of the families we interviewed reported they were not receiving fuel (79%) or nutrition (60%) assistance at the time the interviews were conducted.

Table 2 contains a summary of the children's ages when they received a diagnosis and their ages when their parents were first concerned about their child's development. Twenty-seven (96%) of the participants indicated that they suspected their child was developing atypically before they received a diagnosis of ASD. The majority of the children in this sample were diagnosed before the age of 2 (89%). Three participants reported their child was not diagnosed until the age of 4 or 5.

Table 3 reports information on families whose children were receiving ABA services at the time the interviews

Table 1 Participant Demographics

Demographics	Percent of Sample (<i>N</i> =28)
Mean age (range)	
Mother	34.2 (23–46)
Father	38.3 (24–64)
Child	3.8 (2–8)
Mother's cultural identity	
Dominican	46%
Puerto Rican	36%
Central American	11%
South American	7%
Non-Hispanic	0%
Father's cultural identity	
Dominican	43%
Puerto Rican	32%
Central American	11%
South American	7%
Non-Hispanic	7%
Mother's education level	
High school or less	36%
Bachelor's degree or some college	60%
Master's/professional degree	4%
Not known	0%
Father's education level	
High school or less	36%
Bachelor's degree or some college	54%
Master's/professional degree	4%
Not known	7%
Years living in the U.S.	
Less than 5 years	18%
5–10 years	21%
More than 10 years	61%
Language spoken in the home	
English	11%
Spanish	68%
Both equally	21%
Language spoken to the child	
English	32%
Spanish	39%
Both equally	29%
Fuel assistance	
Yes	21%
No	79%
Supplemental nutrition assistance	
Yes	39%
No	60%

were conducted ($N = 14$). Many of these families reported they were receiving fewer than 16 hr of ABA services per week ($N = 12$). Specifically, 14% of the respondents

Table 2 Child Ages When Parents Suspected a Diagnosis and When Diagnosed

Age of child	<i>N</i>
Diagnosis suspected	
0–12 months	6 (21%)
1–2 years	15 (54%)
2–3 years	5 (18%)
3–4 years	1 (4%)
4–5 years	0 (0%)
Diagnosis received	
0–12 months	6 (21%)
1–2 years	12 (43%)
2–3 years	5 (18%)
3–4 years	2 (7%)
4–5 years	3 (11%)

reported their child received between 22 and 30 hr of ABA, 43% reported their child received between 7 and 15 hr of ABA, and 36% reported their child received 6 hr or less of ABA. Several follow-up questions were asked to determine the reasons families were receiving fewer than 25 hr of ABA services. Factors included the child's age (e.g., if they were enrolled in school, children may have received some form of ABA services as part of their individualized education plan, but no parents reported with certainty this was the case), parents' lack of knowledge about their child's eligibility for additional services, and/or providers' schedules preventing additional hours (as reported by the parents). Half of these parents (50%) reported they did not know whether their child could receive more hours of ABA services. Likewise, half (50%) reported that a therapist was not available at the times they were available, and three quarters of the parents (75%) reported they felt the number of hours their child was receiving was not enough.

As noted previously, half ($N = 14$) of the participants interviewed reported their child was receiving ABA services at the time the interview was conducted, whereas 13 of the participants reported their child was not receiving ABA services. One participant reported they did not know whether their child was receiving ABA services at the time of the interview. If a parent reported their child was not receiving ABA services, we asked whether they knew that this service was available. Four of the participants interviewed indicated they did not know ABA services were available to their child. One participant stated they did not want to have ABA services for their child. Table 4 summarizes the parent-reported reasons for the lack of ABA services ($N = 8$). The primary reasons reported by the participants included (a) the child was on a waitlist (88%), (b) parents had difficulty making an appointment for their child to receive the service (63%), and (c) there

Table 3 Parent-Reported Reasons for Receiving < 25 hr of Applied Behavior Analysis Services ($N = 12$)

Parent response	Agree N (%)
My insurance does not cover more hours of this service.	1 (8%)
I am unable to transport my child to receive additional hours of this service (there is no transport; we must travel long distances).	1 (8%)
I don't know if my child can receive additional hours of this service.	6 (50%)
The service provider is only available for the hours that are currently provided.	6 (50%)
My work schedule comes into conflict with additional hours of this service.	2 (17%)
I believe the hours of this service that my child is currently receiving are enough; I don't want my child to receive more.	3 (25%)

were no ABA services available in their geographic area (50%). A little over a third (38%) of families indicated a need for more bilingual therapists.

When parents reported their child was receiving ABA services, we asked about their overall perception of the services; their replies to the 13 questions related to perceptions about ABA services are summarized in Table 5. Levels of positive agreement were collapsed into one category (i.e., if parents responded that they definitely or somewhat agreed with the statement), as were levels of disagreement (i.e., if parents responded they definitely or somewhat disagreed) and neutral responses (i.e., if parents responded that they neither agreed nor disagreed). In almost every case, the vast majority of parents responded positively to the statements about ABA services their child received at the time of the interview.

Finally, we asked parents several questions related to their perception of the impact of ABA services on their child's behavior. The large majority of parents answered "yes" to questions about the perceived impact of the ABA services their child received, including decreased aberrant or challenging behavior (86%), less severe autism symptoms (93%), and improvement in the child's self-help (86%) and academic (100%) skills. Parents also reported they were learning to help their child (93%) as a direct result of the ABA services

provided. In sum, the parents of children who received ABA services reported overall positive perceptions about the therapy provided to their child.

Discussion

The aims of this pilot study were to explore the experiences of Latino families that have a child with ASD living in Massachusetts and to identify disadvantaging factors that contributed to difficulties in finding or maintaining ABA services for their children. We also sought to determine parental perceptions of the ABA services for those families whose children were receiving these services. Our procedure involved the development of a structured interview that included questions about the child's diagnosis; whether parents had noticed any atypical development in their child before receiving a diagnosis; the services the child was receiving at the time of the interview; and for those families that were receiving ABA services, the number of hours they were receiving services and their overall perceptions of the ABA services provided. We also asked several questions about the families' demographics.

Table 4 Parent-Reported Reasons for the Lack of Applied Behavior Analysis Services ($N = 8$)

Parent response	Agree N (%)
I would like to have this service, but my child is on a waitlist.	7 (88%)
I had difficulty in making an appointment for this service.	5 (63%)
I cannot find a therapist who offers this service in the area where I live.	4 (50%)
There is no therapist who speaks my native language.	3 (38%)
My child no longer qualifies to receive this service because of their age.	3 (38%)
I do not know how to find this service.	2 (25%)
I do not have transportation to get to this service.	2 (25%)
My work schedule comes into conflict with this service.	1 (13%)
There is some other reason.	1 (13%)
My insurance does not cover this service.	0 (0%)
I am concerned that if I look for this service, I will have problems with immigration.	0 (0%)
My family does not believe that this service is necessary.	0 (0%)
My husband/wife/partner does not believe this service is necessary.	0 (0%)

Table 5 Parental Perceptions of Applied Behavior Analysis (ABA) Services (N = 14)

Parent response	Agree N (%)
I would recommend these services to other parents who have a child with autism.	14 (100%)
ABA services improve my own quality of life.	13 (93%)
I am involved in the decisions made about my child's treatment plan.	13 (93%)
ABA services improve my child's quality of life.	12 (86%)
I agree with all of the goals and objectives the therapist is working on with my child.	12 (86%)
My family is in agreement with the services provided to my child.	12 (86%)
I am satisfied with the services my child receives.	11 (79%)
I understand what the therapists are doing when they work with my child.	11 (79%)
The therapist asks for my input when they are creating new goals and objectives to teach my child.	11 (79%)
My partner and I are in agreement about the services provided to our child.	11 (79%)
The therapist who works with my child is able to meet their needs.	10 (71%)
The therapist explains why they are working on certain goals and objectives with my child.	10 (71%)
The amount of time my child receives these services is appropriate.	8 (57%)

The child participants' ages of diagnosis and the ages when parents had concerns about their child's development are promising for this sample. That is, most parents reported that their child received a diagnosis around the time they noted atypical development. Likewise, the majority of the children in this study were diagnosed by the age of 2 years. These findings are in contrast to previous research that has reported racial and ethnic disparities for families of Latino and African American backgrounds (Magaña et al., 2013). However, our sample size is relatively small, and the data for this study were collected in a resource-rich region of the United States. In addition, the demographics of the participants in this preliminary study were skewed toward bilingual-speaking Latino families that had been living in the United States for many years (including parents born in Puerto Rico). These factors may have contributed to families' ability to receive a diagnosis for their child at a younger age.

One third of the families we interviewed were not receiving ABA services, or at least none that the parents could reliably report (e.g., children sometimes receive other services in the school setting, but only one parent interviewed reported that their child was receiving ABA services at school). For families that confirmed their child was receiving ABA services, the majority reported receiving fewer than 16 hr per week. Prior research has reported correlations between the intensity of ABA service delivery and overall outcomes of the services rendered (Linstead et al., 2017; Peters-Scheffer et al., 2010). Specifically, these studies have shown that "low-intensity" ABA services (on average 6.5 hr per week) result in generally smaller improvements in autism symptoms. For example, Peters-Scheffer et al. (2010) evaluated the effectiveness of low-intensity behavioral treatment that supplemented pre-school services for 3- to 6-year-old children with ASD. Treatment gains in terms of developmental age and levels of

adaptive behavior were evaluated, as well as ASD symptom severity, for this group of children compared to a group who participated in regular day care. Symptom severity did not improve following 8 months of the low-intensity ABA services. In a large-scale analysis of both duration and intensity of ABA services, Linstead et al. (2017) investigated how these two variables impacted learning outcomes across several different domains (academic, adaptive, language, motor, social, etc.). Treatment intensity and duration were both predictors of mastered learning objectives across all domains that were evaluated. These results provide support for intensive behavior-analytic interventions (defined as 36 hr or more), which were rarely reported by the families we interviewed.

Although many of the families we interviewed reported that their child attended a public school, they could not verify that ABA services were provided in the school setting. Of particular concern was that some parents reported that they either did not know about ABA services at all or did not know their child was still eligible for ABA home services once the child was enrolled in a public school. An explanation for these findings may be that parents opted to place their child in a full-time school placement immediately following their child's third birthday, when early intervention home services ended. ABA services that are provided as part of state-funded early intervention services are generally easier to acquire because of the funding source. In addition, for parents whose children were receiving ABA services, a few reported anecdotally that services were not available on weekends, which were a preferred time for them. Future research should include interview questions that query factors such as the time of service provision to determine whether this is a common factor for Latino families and/or families in general.

On a more positive note, parents were generally very satisfied with the services and their child's provider regardless of

the number of hours provided to children receiving ABA services. In addition, parents indicated that the ABA services directly benefited their own quality of life and that of their child in various ways (i.e., social, academic, building independence). Parents also reported positive feedback regarding the quality of the services rendered by the provider. This finding is promising, given recent evidence indicating that families that have a strong therapeutic alliance with providers are also more likely to implement recommended strategies when the provider is not in the home (Parish et al., 2012). Notably, parents also agreed that they would recommend ABA services to other parents who had a child with ASD.

Limitations and Future Directions

Some limitations of the study should be noted. First, this was a small sample, and the parents had a relatively high level of education (i.e., 61% of mothers and 54% of fathers reported they had attended some college or completed a bachelor's degree). Education may be related to parents' overall health literacy and the ability to advocate for their child (Yin et al., 2009). Second, parents interested in participating in this research were required to initiate contact with the researchers. Presumably, all participants included in this study were comfortable contacting the research team and did not endorse the statement "I am concerned that if I look for [ABA services], I will have problems with immigration," which may suggest that families that were concerned with immigration did not reach out to participate. It is worth noting that this limitation has been found in other studies (e.g., Jang & Vordertrasse, 2019). Third, as stated previously, many of the families we interviewed reported that they spoke both English and Spanish in the home and to their child (i.e., 64% spoke either only in English or both English and Spanish equally to their child, despite reports that all families were fluent in Spanish). Thus, parents' ability to communicate in English may have facilitated their access to ABA services. For these reasons, our sample was not likely representative of the Latino population in Massachusetts or nationally. Nonetheless, our findings point to some potential disadvantaging factors related to the receipt (or nonreceipt) of ABA services in our sample, who are likely better educated than the Latino population as a whole. Future research with a larger, more representative sample might reveal that these and other disadvantaging factors are impacting Latino families that have children with ASD.

Though we made specific attempts to recruit a larger and more diverse population of participants with regard to educational and socioeconomic backgrounds, our methods did not yield the sample we would have preferred. In the present study, we posted flyers in the community (e.g., laundromats, libraries); sent flyers to early intervention providers who regularly work with families of diverse cultural, linguistic, and socioeconomic backgrounds; and advertised the study in

Spanish-language newspapers and radio stations. In addition, we provided each family with a physical copy of the recruitment flyer following the interview and asked them to share the information about the study with their own networks. Though this was somewhat successful, future studies may need to employ more strategic snowballing sampling methodologies to increase the number of participants. This method may be particularly helpful for hard-to-reach communities (Valerio et al., 2016). Alternatively, future researchers may benefit from collaboration with medical providers (i.e., pediatricians) and providers that deliver diagnostic services (i.e., large hospitals) that have direct contact with families of young children. These collaborations may lead to larger and more diverse participant pools that are representative of the Latino population in the United States. Finally, we did not recruit a comparison group of non-ethnic-minority families to compare their experiences and perceptions of ABA services with those of Latino families. Similar studies have been published on this topic (Grindle et al., 2009), but to our knowledge, no studies have focused on Latino families' experiences and perceptions of ABA services.

Because half of the participants interviewed reported they had access to ABA services, the information about possible disadvantaging factors is limited to the other half of the participants recruited for this study. Future research should aim to recruit samples of sufficient size to enable the evaluations of demographic differences between families that are receiving ABA services compared to those that are not receiving ABA services. The small sample size in the current study does not allow for such comparisons, but we identified factors that families not receiving services reported, in an effort to describe these families' experiences with ABA services specifically. Although other studies have examined access to services generally for Latino families of children with ASD (Broder-Fingert et al., 2013; Flores & Tomany-Korman, 2008), there is very limited research focused on Latino families' access to and experience with ABA services more specifically (Angell et al., 2016). In addition, we included parental perceptions of the ABA services, which have also received minimal attention in the published literature to date.

The research described here should be replicated with families from different racial and ethnic groups and with families living in different regions of the United States in an effort to evaluate the experiences of families receiving ABA services more broadly. The Latino population comprises about 12% of the entire population of the Commonwealth of Massachusetts (U.S. Census Bureau, n.d.). Reports suggest that 69% of Massachusetts's Latino population are native born and 22% speak only English at home, whereas 78% speak a language other than English at home (Pew Research Center, n.d.). These demographics align with the demographics of the sample of Latino families we interviewed for this project. That is, 21% of the families we interviewed reported that they spoke

both English and Spanish at home, and 61% of the families reported they had been living in the United States for at least a decade. Published reports using national data suggest that racial and ethnic disparities relative to access to care, referrals, number of service hours, and unmet needs exist for Latino families of children with special health care needs, including ASD (Smith et al., 2020). Few published reports on Massachusetts service trends exist. One study by Broder-Fingert et al. (2013) found that Latino children experienced lower rates of specialty care, including neurologic and related testing, EEGs, brain MRIs, sleep studies, and neuropsychiatric testing compared to White children. Singh et al. (2009) examined geographic disparities in access to a medical home (National Resource Center, n.d.) for children (birth to 17 years of age) with special health care needs, and found that children living in Massachusetts had a half again higher odds of not having access to a medical home (53%). Latino children's odds of not having access to a medical home were even higher. Thus, despite Massachusetts being a relatively resource-rich state, not all resources are equitably distributed.

Given the diversity that exists *within* the Latino population, replications of the present work will also bring added value to this area of research. Latinos are united by one common variable—their ancestry can be traced back to a Spanish-speaking country. The Latino community is otherwise composed of a diverse group of people with many different nationalities, customs, and cultural practices. In addition, variables such as education, immigration status, self-identification, and years living in the United States contribute to acculturation that further complicates what it means to be “Latino.” In this study, 61% of the participants reported living in the United States for over a decade, with a percentage of those families reporting they were U.S. citizens (born in Puerto Rico). The number of years living in the United States may be correlated with better overall access to health care and knowledge of specialty services. Future research on this topic should evaluate disparities that exist within Latino communities, with immigration status and the number of years living in the country as important variables to consider.

As has been noted, the interviews conducted for this study took place in Massachusetts, which is a resource-rich region of the United States. For example, under the Massachusetts ARICA law (An Act Relative to Insurance Coverage for Autism, 2010), private health insurers are required to provide coverage for the diagnosis and treatment of ASD. In addition, following the passage of the Autism Omnibus Bill, (2014), a landmark bill that addressed the unmet needs of individuals with ASD, the Massachusetts Medicaid and Children's Health Insurance Program (combined into what is known as MassHealth) also began covering ABA services in 2015. For these reasons, it is likely that the results of our sample are more favorable than they would be in other regions of the

United States that do not have the same available resources. However, it is important to highlight that although these resources exist within the state, some parents reported a lack of awareness about their child's eligibility to receive ABA services because of either their age or their school placement. In addition, parents noted the lack of ABA services in their geographic area as a concern. Anecdotally, this concern about a lack of ABA service providers in the geographic region where the interviews were conducted was validated by the authors. In other words, this concern was not due to a lack of information about the services that were available in the region at the time the interviews were conducted. Future research should evaluate racial and socioeconomic disparities in cities/towns where ABA services are and are not rendered.

Implications for Practice and Policy

The findings from the present study suggest specific ways in which practice and policy could be improved. For example, early intervention and other service providers should be encouraged to educate parents on their entitlements to services, perhaps with repeated reminders and information sessions about these services. Increased collaboration among early intervention providers, early childhood educators working in schools, and ABA service providers may help to address these concerns. In addition, ABA service providers may extend their outreach to areas where these types of services (both in home and center based) are not readily offered, especially if this outreach will also increase the likelihood of recruiting entry-level therapists who speak the families' primary language, which was also noted as a potential barrier by some parents in this study. Importantly, these concerns have been noted in other research and have been a source of discussion for practicing professionals in recent years (Connors et al., 2019).

Despite the limitations noted, the study also has several strengths. In this pilot study, a structured interview was developed that probed parents' experiences with and perceptions of the services their children received and was delivered in English or Spanish according to parental preference. Parents interviewed for this study generally received a timely diagnosis for their children, although parents also reported lengthy wait times to access ABA services. This finding is in line with a recent report published by the Behavior Analyst Certification Board (BACB, 2021), which listed Massachusetts as second with the most increased demand for Board Certified Behavior Analysts and Assistant Behavior Analysts (BACB, 2021). The data reported here confirm that lengthy wait times are problematic for Latino families, though we cannot report if the wait-times are longer for these families in particular. Moreover, this pilot work can serve as a foundation for the development of semistructured interviews in future research. There is an advantage to asking about and making attempts to understand the lived experience of participants in their own words. The

descriptive research helps inform current practices and policies to begin to address ongoing disparities in access to ABA services.

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Declarations

Ethical approval This study was performed in line with the principles of the Declaration of Helsinki. Approval was granted by the institutional review board at the University of Massachusetts, Lowell.

Conflicts of interest The authors declare no conflicts of interest.

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