

Ethnic Disparities in Diagnosis, Interventions, and Conceptualizations of Autism Spectrum

Disorder in Texan Families

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Honors Thesis

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DEDICATION

This thesis is dedicated to all the families, parents, siblings, and extended families, of an individual with autism spectrum disorder. May this be a small step toward getting the world and ourselves to better understand these amazing individuals.

Mi tesis se lo dedico a todas las familias, los padres, hermanos y familias extendidas de algún individuo con el trastorno del espectro autista. Espero esta investigación aporte un escalón mas al entendimiento de estos inspiradores individuos.

Abstract

Surveillance summaries suggest that White children are more likely to be identified with autism spectrum disorder (ASD) compared to Latinx children. Previous research suggests that disparities in the access, treatment, and understanding of ASD between ethnicities may contribute to this result. An increased amount of disparities is associated with a longer and more confusing diagnostic process, less accessibility and information, and negative conceptualizations of ASD. There is, however, a lack of research directly comparing disparities in the state of Texas. Using a needs assessment survey, I analyzed the disparities in diagnostic process, interventions and services, and conceptualizations of ASD between White, U.S. born Latinx, and Latinx immigrant families of Texas. I hypothesized that overall White children have the least amount of disparities, a faster diagnostic process, more access to interventions and resources, and more positive conceptualizations of ASD, followed by U.S. born Latinx and then Latinx immigrants. Contrary to my hypothesis, results suggested that U.S. born Latinx children in Texas were the ethnicity with most differences compared to Latinx immigrant and White children. Knowledge of these differences or disparities can help health care services improve confusing diagnostic processes, provide more bilingual initiatives, and ensure that all ethnic groups in Texas have equal access to services to further the developmental outcome of their children.

Keywords: Autism spectrum disorder (ASD), ethnic disparities, diagnosis, intervention, conceptualization, Texas

Ethnic Disparities in Diagnosis, Interventions, and Parent Conceptualizations of Autism
Spectrum Disorder in Texan Families

Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by deficits in social communication and interaction, repetitive behaviors and restricted interests (National Institute of Mental Health, 2018). The prevalence of ASD has been rising, with recent statistics suggesting that 1 in 59 children up to the age of 8 met the diagnostic criteria for ASD (Baio et al., 2018). Reports according to the Health and Human Services Commission's Center for Strategic Decision Support estimated in 2014 that 399,915 individuals, including 130,316 children aged 22 or younger, had an ASD diagnosis out of the 7 million children living in Texas (Lee, Deviney & La Sohn, 2016; Texas Council on Autism and Developmental Disorders, 2016). However, diagnostic disparities are present between White and Latinx families. White children are 1.2 times more likely to be diagnosed with ASD than Latinx children (Centers for Disease Control and Prevention, 2019). Furthermore, Latinx children were diagnosed 2.5 years later than White children (Mandell et al., 2002).

The present study examined whether different ethnicities had differences or disparities in the diagnostic process and accessibility to services for families with children with ASD. Furthermore, it also analyzed the differences in conceptualizations and beliefs of immigrant Latinx, U.S. born Latinx, and non-Latinx White parents of children with ASD. White and Latinx parents of children with ASD hold different views of the disorder, its symptoms, and the resources available to them (Zuckerman et al., 2014; Pederson et al., 2012). This affects the parent's conceptualization of ASD, the mental image that they construct about ASD, how it manifests, how it affects the families, and its treatments and interventions. For example, Zuckerman et al. (2014) conducted focus groups and interviews with 30 parents of typically

developing Latinx children. The parents were shown vignettes of a Latinx mother concerned with her son's behaviors, which remarkably resembled behaviors associated with ASD.

Zuckerman et al. (2014) reported that Latinx parents differed from White parents in their expectations of children with and without disabilities. Latinx parents tended to focus much more on whether their child was respectful and responsible, while White parents tended to focus on whether their child was reaching typical developmental milestones (Arcia et al., 2000). These differences in expectations held by Latinx families may relate to their overall view of symptoms of ASD and raise the possibility whether they contribute to the delay in identification of ASD among Latinx children (Zuckerman et al., 2014).

Parents, as their child's primary caregiver, play a crucial role in their development; a parent's failure to detect signs of ASD can delay a child's intervention and treatment, thus, inhibiting the child's development (Baio et al., 2014; Ijalba, 2016). Although differences in parent's conceptualization of ASD have been raised as a possible reason for identification, intervention, and treatment disparities in Latinx and White children with ASD, a direct comparison between them is lacking. Furthermore, scant research has been conducted on U.S. born Latinxs and immigrant Latinxs in the state of Texas. The distinction between U.S. born Latinxs and immigrant Latinxs is important because both represent very diverse groups. Becerra et al. (2014) found a substantial difference between the two group's mean age of ASD diagnosis. To further investigate if ethnicity is linked to a difference in mean age of diagnosis or any part of the diagnostic process, this study examines the disparities related to ASD between White, U.S. born Latinx, and immigrant Latinx populations in Texas. The research combines and expands on ethnic differences of ASD in terms of the diagnostic process, resources and interventions, and parent conceptualizations about the disorder.

Autism Spectrum Disorder

Autism spectrum disorder is a neurodevelopmental disorder that affects a child's thinking, communication, and behavior in all aspects of their life. ASD can be diagnosed at any age, but symptoms usually begin within the first two years; however, it is usually diagnosed in late infancy or early childhood. The disorder is a spectrum because of the range of intensities, manifestations, and symptoms (National Institute of Mental Health, 2018). Across the spectrum, ASD impairs the ability to engage and function in everyday life. A child with mild ASD can have a high IQ and participate in sports but have difficulty understanding a peer's sarcasm or trying new foods. On the other hand, a child with severe ASD can be non-verbal, make no direct eye contact, and require substantial support to function in everyday life.

An interaction between genetics and the environment is thought to underly ASD and differences in its manifestation (Pederson et al., 2012). Thus, cultural context and conceptualization can be potential environmental contributors to differences in ASD. ASD occurs across all ethnic, racial, economical, and cultural groups, but there is limited information on the key differences of how its prevalence, identification, and interventions vary across ethnicities (Center for Disease Control and Prevention, 2019; National Institute of Mental Health, 2018). So far, differences in diagnosis of ASD have been associated with maternal race/ethnicity, parent knowledge of ASD, and stress of diagnostic process (Becerra et al., 2014; Zuckerman et al., 2017; Zuckerman et al., 2014).

Disparities

The term disparity is most commonly used to describe a variation or difference. However, when applied to health, disparities are differences in health that adversely affect socially disadvantaged groups according to population characteristics such as race, religion,

wealth, and ethnicity (Braveman et al., 2011). To be socially disadvantaged is to have unfavorable conditions socially, economically, or politically. Furthermore, the population affected is limited in the extent that they can utilize and access all services, resources, and benefits available (Braveman et al., 2011). In terms of this study, disparities could arise if there are significant differences in a group's outcome in the diagnostic process of ASD, the extent of access and use of ASD resources and services, and any negative beliefs about ASD that could be of social disadvantage to the group. Health disparities are also potentially avoidable, therefore researchers should aim to identify them and then aim to reduce and eliminate them (Braveman et al., 2011).

Autism Spectrum Disorder and Variations Across Populations

Some research has been conducted suggesting variations across populations. Pederson et al. (2012) focused on studying the prevalence of ASD in a large cohort of 8-year-old Latinx and White children in the Arizona area. Demographics from the study showed White populations made more than the U.S. national average income and were mostly part of the middle socioeconomic class. This population was also more likely to be medically insured, usually had more access to formal education, and had a higher prevalence of ASD. Findings similar to Pederson et al. (2012) supported their conclusion that Whites had the largest prevalence of ASD, but, also identified that there is a significant gap in the prevalence (number of individuals diagnosed) of ASD in White and Latinx populations (Baio et al., 2018). Pederson et al. (2012), additionally found that ASD prevalence for Latinxs was becoming substantially closer to that of non-Latinx Whites in previous years, indicating that the gap in prevalence between the groups is decreasing. This is not necessarily because there are more White children with ASD, but rather that ASD is more readily identified and the White population faces fewer barriers (Angell et al.,

2018; Baio et al., 2018; Zuckerman et al., 2017). Zuckerman et al. (2017) utilized surveys of 352 families of children with ASD in the U.S. to compare the barriers faced by White populations and Latinx populations. Results found that on average, White populations faced fewer barriers to access of treatments for ASD, parent beliefs, language, and stress of diagnostic process.

Baio et al. (2018), conducted a surveillance of prevalence of ASD across 11 sites in the United States and found that Latinx populations were the group that were least likely to be identified with ASD. Latinxs were on average diagnosed 2.5 years later, were also more likely to be misdiagnosed, and had more severe symptoms at the time of diagnosis than White children (Zuckerman et al., 2014; Mandell et al., 2002). This may be influenced by the fact that many studies do not reach Latinx communities with limited access and are based in costly health-care facilities that may not be attainable for Latinx populations with lower incomes. In support, Magaña et al. (2012) analyzed a national survey (N= 4,414) to examine ethnic disparities in children with ASD and found that Latinxs were less likely to have health insurance to cover costs of specialists. Specialists were also less prone to give an ASD diagnosis to this population due to language barriers (Zuckerman et al., 2014; Magaña et al., 2012). They were also more likely to have more barriers associated with stress from diagnostic process, access to treatments, and parent knowledge (Baio et al., 2018; Zuckerman et al., 2017). Overall, these studies suggest that the difference in ASD between Whites and Latinxs may be associated with economic barriers, language barriers, and stress associated with ASD.

U.S Born versus Immigrant Latinxs. Understanding the differences associated with U.S. born Latinx and immigrant Latinx families is essential in developing a better understanding of the relationship between ethnicity in the diagnosis, interventions, and beliefs of ASD. Distinguishing between the two may help identify the extent to which living in the United States

has influenced these population's view of ASD. For the purposes of this study, U.S. born Latinxs will be parents who identify as Latinxs but were born in the United States. Immigrant Latinxs will be parents who identify as being Latinx but do not identify as White or having been born in the United States. Angell, Empey, and Zuckerman (2018) conducted a review of ASD prevalence and summarized that disparities in ASD may be linked with culture and research suggests that culture between U.S. born Latinxs and immigrant Latinxs vary (Zuckerman et al., 2017; Ijalba, 2016; Becerra et al., 2014). Ijalba (2016) conducted interviews with 22 Latinx immigrant mothers and found that stigmatization, isolation, lack of resources, and preconceptions of ASD deeply challenged their experience with ASD. Mothers were reluctant to even speak their native Spanish language with their child for fear of causing more language difficulties. The economic hardships, immigration difficulties, and language barriers faced by Latinx immigrant mothers form a unique set of factors that influence the diagnosis process, interventions and resources, and parent beliefs of ASD (Ijalba, 2016). Furthermore, Zuckerman et al. (2017) conducted a study that focused on analyzing the barriers in diagnosis and treatment between White families, Latinx families with English proficiency, and Latinx families with limited English proficiency. Compared to White families, Latinx families with limited English proficiency were much more dissimilar than Latinx families with proficiency in English, suggesting differences in barriers faced within Latinx groups. Overall, these studies suggest cultures between U.S. born Latinxs and foreign born Latinxs do vary; dividing Latinxs into two groups may be beneficial to further identifying barriers to ASD.

Becerra et al. (2014) conducted a population based study in the Los Angeles County comparing children diagnosed with ASD to the total amount of children born within 1998-2009. As a result of the study, researchers identified the need to further examine the role that nativity

and immigration may play in the identification and diagnosis of ASD. Some research has suggested that disparities of ASD prevalence shown between Latinx populations and White populations can have a basis in economic differences (Pederson et al., 2012). However, Angell, Empey, and Zuckerman (2018), summarized that even after controlling for socio-economic factors, there still seemed to be prevalent evidence of ethnic disparities in ASD. Ultimately, research has been conducted on a national basis, but is lacking in analyzing the ethnic disparities that can be found within the populations of the state of Texas.

Treatments and Interventions

Early evaluation, diagnosis, and intervention of children with ASD are important to ensure the child receives the best chance of reaching their maximum potential. Ethnic disparities in the access and use of treatments and interventions, however, have also been suggested by past research. The Center for Disease Control and Prevention (2019) found that 85% of parents were concerned about their child's development by the age of 3 but only about 42% were evaluated. Although the average age of diagnosis was 4.5, 30% of children had still not received a formal diagnosis until age 8. Among Latinx populations, there was almost no awareness of intervention and treatment services for early intervention of ASD (Zuckerman et al., 2014). Latinx parents often suggested general doctors, friends, family, teachers, and churches as good sources of information for any problem they saw in their child, causing a delay in reaching health care professionals (Zuckerman et al., 2014). Late evaluation and diagnosis can limit the child with ASD from the crucial early intervention resources available.

Further research suggests that Latinx children with ASD face greater challenges in receiving high-quality health care, including health services, that are linked to better health outcomes (Magaña et al., 2012). Moreover, a study conducted by Dubay, Watson, and Zhang

(2017) on 28 Latinx and 27 White families found that even if interventions were available to populations other than Whites, the interventions were incongruent with each population's culture. Interventions were made and tested based on the idea that a White upper-middle class family would be receiving them, many times lacking in feasibility and applicability for Latinx families. These studies emphasize the need for specific and culturally modified interventions for each population (Dubay, Watson, & Zhang, 2017; Magaña et al., 2012). Interventions and treatments have the potential to address the disparities among ethnicities like White, U.S. born Latinxs, and immigrant Latinx populations. The results of studying the disparities between these populations can guide interventions and effective outreach approaches, minimizing the disparities present between these ethnicities.

Conceptualization

Understanding the conceptualization of ASD of populations is important because it helps understand their approach to the diagnosis process, interventions, and their beliefs (Pedersen et al., 2012). A parent's conceptualization can be the mental image constructed about their child's disorder, their definitions of the disorder, how it manifests, and treatments and interventions. Donovan and Zucker (2017) illustrated how the conceptualization of ASD for the population during the 1960s affected a parent's approach to their child's diagnosis. The term "refrigerator mothers" was frequently utilized to imply that a mother's coldness or lack of love toward her son or daughter was the cause of their ASD. For the child to receive treatment, the mother had to agree to treatment as well as she was part of the problem (Donvan & Zucker, 2017). Although parents and professionals later strayed from the conceptualization of refrigerator mothers, this belief influenced the family's approach to a diagnosis, receiving treatment, and the community's beliefs about ASD.

Other studies have analyzed conceptualizations of White and Latinx families and found core differences in cultures that link to ASD. According to Zuckerman et al. (2014), about one third of Latinx, or Hispanic, families in Oregon had never heard of ASD or any of its symptoms and manifestations. Many assumed that if the child presented with any symptoms of ASD it was due to dysfunction in the family and was dealt with as a family matter instead of seeking professional care. Families also tended to hide and deny acknowledging a disability in the family because it was associated with embarrassment, rejection, and family burden. Some of the early signs of ASD were associated with a lack of love or the need for more parental attention for the child. Some families even stated that behavior problems of children were family problems and not “doctor’s stuff” (Zuckerman et al., 2014). When families did reach out to health care providers, about 51% of the time Latinxs felt that providers were not sensitive to their family values and customs (Magaña et al., 2012). Beliefs such as the ones described above can play a role in Latinx families’ lack of recognition of their child’s need for an evaluation.

Conclusion

The current study aims to identify any disparities or differences between White, U.S. born Latinxs, and immigrant Latinx ethnic groups. Specifically, aiming to look into the diagnosis process, interventions, and parent beliefs of ASD. Disparities are potentially avoidable differences that affect socially disadvantaged groups (Braveman et al., 2011). By recruiting parent participants throughout Central Texas, researchers gained demographic information about each participant and their family along with responses about ASD process, resources, and beliefs. In order to further investigate the role ethnicity and nativity play on these disparities, Latinx groups will be divided into U.S. born and immigrants. Similar to previous research, the study investigates if Latinx immigrants are the ethnic group with most disparities.

DESIGN & METHODS

Needs Assessment Survey

Design Overview. The study hypothesis is that ethnicity is linked to disparities in diagnostic process, interventions received, and parent conceptualization of ASD. Specifically, this study analyzed if U.S. born Latinxs and immigrant Latinx families of children with ASD were diagnosed at an older age, have longer diagnostic processes, less access to interventions, and more negative conceptualization of ASD than White families. Data for this study was collected using a specific needs assessment survey of ASD that was filled out by parents of children, teenagers, or adults with ASD throughout Central Texas. The primary independent variable was ethnicity and the dependent variable categories were responses retrieved from questions about the diagnostic process, interventions and treatment, and parent conceptualizations.

Participants. Advertising, direct contact, referrals, and organizations in the state of Texas were used to recruit parents of children with ASD from local Austin ASD societies, organizations, and health care professionals for participation. The contacts within these organizations then promoted the surveys in either electronic form or paper copy using informational flyers. This same approach was used to spread surveys near the San Marcos, the Rio Grande Valley areas, and northern Texas areas. Survey results yielded a diverse population of White (n=53), U.S born Latinxs (n=19), and immigrant Latinx (n=12) parents (n=84). Out of the total participants, 63.1% identified as White, 22.6% identified as U.S. born Latinx, and 14.3% identified as Latinx immigrants. Characteristics were gathered from the caregivers filling out the forms and their child with ASD. There were 110 survey participants but some were

excluded because participants did not answer demographic questions regarding origin to determine ethnicity.

Table 1.

Participant Country of Origin

	Latinx Immigrant	Latinx U.S. Born	White
Sample Size	n=12	n=19	n=53
Country of Origin			
U.S.	0	19	53
Mexico	9	0	0
El Salvador	2	0	0
Honduras	1	0	0

For this study, American Psychological Association standards for racial and ethnic identity were utilized. White populations are defined as any person of white skin and European, North African, or Southwest Asian descent in the United States. They self-identified on the needs assessment survey as not Hispanic or Latino, described their race as White, and checked that they were born in the United States. Any participants identifying themselves as Hispanic/Latino on the survey will be counted as Latinxs. U.S. born Latinxs will be defined as those that have identified as Hispanic/Latino and have been born in the United States. Lastly, immigrant Latinxs will be those parents who identify as Hispanic/Latino and living in the United States but do not identify as White or having been born in the United States.

Measures

The materials used in this study consisted of a survey, “Identifying Needs Among Texan Children with Autism Spectrum Disorder.” This is a needs assessment conducted through the

University of Texas at Austin and created by the Autism and Neurodevelopmental Disabilities Lab (appendix A). It is a 16-page survey that asks about children with ASD's diagnosis process, evaluation process, information and resources, services and interventions of ASD, parental and communal beliefs, and family demographics. The overarching themes used were the diagnosis process, interventions and services, and parent conceptualizations. No previous information or results based on this assessment have been published.

Diagnostic process. The items that make up this section pertain to the child's ASD, diagnosis process, and diagnosis providers. The diagnostic process begins the moment that the parent begins to notice atypical behavior in their child up to receiving a medical diagnosis of ASD and beginning interventions and services. These items inquire about the age of the child, when the parent first noticed the symptoms, the health care providers' first response, what professionals were visited, and parent beliefs before and when their child was diagnosed with ASD. All questions require answers as dates ($n=3$), answers that can be checked off ($n=2$), or Likert scale ($n=3$). For example, parents will be asked when the child was diagnosed, which would require a numerical answer for the amount of years and months the child was. Following, the parents are asked what professional diagnosed their child with ASD; the survey provides seven answers with adjacent boxes that can be checked off: a developmental pediatrician, primary care physician, neurologist, psychologist, psychiatrist, school psychologist, or other (Figure 1).

Interventions and resources. Survey components that make up this measure include the parent's useful sources for gathering ASD information, supports and therapies that were made available to them, and accessibility of these services. This section asked participants about their child's current therapy including access to ABA and other medications/treatments. Checkboxes

(n=4) are used to indicate whether the service or intervention was received. Participants are also asked for answers in a Likert scale (n=1). For example, parents were asked “Does your child receive all the therapy services needed?” Parents can then respond in one of five ways: definitely not, somewhat no, somewhat yes, definitely yes, or I do not know (Figure 2). This section includes nine questions with sub questions.

Parent beliefs and knowledge about ASD. Items in the survey section ask about parent’s beliefs about disparities in prevalence, diagnosis, and treatment of ASD. These sections include checkboxes that are in Likert scale (Figure 3) from number one to five to indicate to what extent parents agree or disagree with common beliefs about ASD. Statements in this section relate to whether ASD is a lifelong disorder, the influential power each parent has over their child and their disorder, religious affiliation to the disorder, and how they interpret the community views children with ASD. After each of these statements, participants fill out the extent to which they agree or disagree (n=3). For example, a statement will say “For me, my child’s autism is a mystery,” and parents can check (1): “does not apply,” (2): “strongly disagree,” etc. Parents are also given the opportunity in this section to specify any strong additional beliefs they feel were not included in the survey.

Family demographics. This section will allow researchers to collect data relating to the population and particular groups participating in the survey and intervention. Parents will identify ages, income, education, nativity, and marital status for themselves and their child (n=13). Responses from this section determine which ethnic group the participant will fall under.

Data Transformation

Data was scored according to the type of question: (1) Coding of each of the written responses into categories occurs that can be analyzed based on numerical answers such as 0, 1, or

2. For example, if participants answered “yes” to the question that inquired whether they identified as Hispanic or Latino, then 1 would be coded; if participants answered “no” then 0 would be coded. Similar scoring will be utilized to code for parent’s education level (Table 3).

(2) For responses that yield a date or numeric answer, transformation were used to create a number with decimal places for each answer and then used to calculate the means for each of the 3 groups. (3) For responses that only allowed one checkbox to be marked, there would be a score of 1 for the singular checked box (Figure 1). The 1s for each question answer were then tallied up to produce the percentage of participants of each group, Latinx immigrant, US born Latinx, or White, to have selected each box. (4) For scoring Likert scale questions, the choices of answers were grouped. Strongly Disagree received a value of 1, Disagree received a value of 2, Agree received a value of 3, and Strongly Agree received a value of 4. Does not Apply received a value of 0. When the participants selected a box, the number would show up on the data analysis. 1 and 2 were grouped as disagree and 3 and 4 were grouped as agree. Therefore, to obtain the percentage of participants that felt their child was a mystery, all of the agree and strongly agree (group of “agree” and answers 3 and 4) were counted (Figure 3). The percentage would become the amount of participants from each group that checked off these answers. This scoring method was also utilized for questions with Likert scales from: Definitely Not to Definitely Yes (Figure 2).

Table 2

Dependent Variable Categories and Corresponding Survey Items

Dependent Variable Categories	Corresponding Survey Items
Diagnostic process	Your Child’s ASD & The ASD Diagnosis Process (Figure 1)

Interventions, Resources, and Information

Your Child’s Current Therapy and Services, & Access to ABA Services (Figure 2)

Parent and Community Conceptualizations

Parent Beliefs about ASD & Community Views and Knowledge about ASD (Figure 3)

Family Demographics

Questions about Your Child with ASD & Questions about You (Table1)

7a. What professional gave your child the diagnosis of autism spectrum disorder?		
<input type="checkbox"/> Developmental Pediatrician	<input type="checkbox"/> Primary Care Physician	<input type="checkbox"/> Neurologist
<input type="checkbox"/> Psychologist	<input type="checkbox"/> Psychiatrist	<input type="checkbox"/> School Psychologist
<input type="checkbox"/> Other (specify): _____		

Figure 1. Your Child’s Autism Spectrum Disorder (ASD) Example Question. Diagnostic Process example question.

	Definitely Not	Somewhat No	Somewhat Yes	Definitely Yes	I do not know
18. Does your child receive all the therapy services he/she needs?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Figure 2. Your Child’s Current Services and Therapy. Interventions example question.

	Does not Apply	Strongly Disagree	Disagree	Agree	Strongly Agree
24d. My child’s ASD is a mystery to me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Figure 3. Parent Beliefs about ASD. Parent conceptualization example question.

Table 3.*Sample Participant Demographics Data*

Participant #	Age (in years)	*Sex	Country of Origin	**Education
01	39	1	Mexico	1

*Sex = code 0 if male, code 1 if female. **Education = code 0 for High School or Less, code 1 for Some College or College, code 2 = Graduate/Professional Degree

Procedure

Survey data collected from the beginning of 2019 to the end of 2019. These families either submitted the surveys online or completed the surveys on paper. Results from the surveys and previous research allowed for analysis of survey responses in the spring of 2020.

Statistical Analysis

Data collected both in electronic and paper form was entered into a software program. All electronic submissions were done via Qualtrics and checked for accuracy. Data was analyzed using the SPSS system that allows for conversion of the raw data into coded data and for conducting several descriptive and inferential statistics. Means and percentages were computed as descriptive data from questions asking from the four dependent variable categories. For the diagnostic process category, questions regarding a caregiver's or child's characteristics and ages, a professional's responses, professionals who gave the ASD diagnosis, and participants views before and during the diagnosis. For the interventions category, questions about services and therapies received, ABA therapy, and other medications or treatments. For the conceptualization category, questions inquiring about parent beliefs about ASD, beliefs about the diagnostic process, and community beliefs were included. Lastly, the demographics section included questions about the caregiver and child's characteristics such as ethnicity, age, and support needs. For the inferential statistics in the demographics section, univariate ANOVA tests were

utilized to test for significance. Equal variances assumption was tested for using Levene's test and Tukey HSD test conducted as a Post-Hoc. If Levene's test found that variances were not equal, then a Games-Howell Post-Hoc test was conducted. Additional t-tests were conducted as Post-Hoc if univariate ANOVA tests were significant. Three separate t-tests were conducted comparing the descriptive statistics of: Latinx immigrants to Whites, Latinx immigrant to US born Latinx, and US born Latinx to Whites. All descriptive statistics were tested for significance at a $p = .05$ value.

Chi-squared tests, although intended to be utilized to find significance between the groups for interventions and conceptualization dependent variable categories, were not utilized. Chi-squared tests runs on the condition that each sample has to have at least five participants ($n = 5$), which was not always true for the sample of Latinx immigrants and Latinx U.S. born.

RESULTS

Participant Characteristics and Demographics

As seen in Table 5, there were significant differences in the caregiver characteristics and child characteristics of the 84 participants. Latinx immigrants, Latinx US born, and White groups varied in the age of the caregiver. Significance tests showed a significant difference ($p = .004$) in caregiver age between Latinx immigrant caregivers ($n = 12$) and White caregivers ($n = 53$) and Latinx U.S. born ($n = 19$) with White caregivers ($n = 53$). There was no significant difference between the groups in caregiver sex or number of children with ASD in the household. Income ($p = .000$) and education level ($p = .000$) did have significant differences across all three groups for FPL (federal poverty level) and education level (high school or less). Significance tests found differences in children participants in terms of age ($p = .027$) between Latinx immigrants and White. There were no significant differences for child characteristics for sex (males) or child support needs. Child support needs are based on 3 levels according to the ASD spectrum. Level 1 represents the individual requiring support, level 2 represents the individual requiring substantial support, and level 3 represents the individual requiring very substantial support. There were however significant differences in the amount of participants between Latinx immigrants and White populations to have Medicaid insurance ($p = .049$). As anticipated, Latinx immigrants had overall the most differences from the other two participant groups. Table 5 shows the demographic measures across the sample.

Table 5*Survey Participant Characteristics*

	Latinx Immigrants (n = 12)	Latinx US Born (n = 19)	White (n = 53)	P – value
Caregiver Characteristics				
Age (in years)	39.0*	40.2 ⁺	46.7* ⁺	.004
Sex (% Female)	100%	94.7%	90.6%	n.s.
# of Children with ASD in Household	1.33	1.05	1.17	n.s.
Income (% ≤ 200% FPL)***	83.3%	38.9%	12%	.000
Education (% HS or less)***	66.7%	15.8%	7.5%	.000
Child Characteristics				
Age (in years)	9.0*	10.1	13.0*	.027
Sex (% Male)	100%	84.2%	77.4%	n.s.
Insurance (% Medicaid only)	81.8%*	52.6%	41.5%*	.049
Child Support Needs (% requires significant support)	50.0%	66.6%	47.2%	n.s.

Note: *** indicates significance between all groups. * indicates significance at $p < .05$ with Latinx Immigrants. ⁺ indicates significance at $p < .05$ with Latinx US born. N.s. means not significant across all three groups on ANOVA. All three groups are different from each other. The first line shows that each of the Latinx groups are significantly different from the White but not from each other.

The Diagnostic Process

The diagnostic process entailed the moment parents first noticed atypical behavior in their child to receiving a medical diagnosis to actually beginning interventions and services. Figure 4 outlined the process of diagnosis which was marked by three points: age of first concern, age parents first told a medical doctor, and age of diagnosis. Overall, U.S. born Latinx had the shortest diagnostic process, followed by Latinx immigrants and Whites. However, there were no significant differences across the diagnostic event and age between the groups. The difference in age of diagnosis between White participants and Latinx U.S. born was the closest to reach significance ($p = .063$)

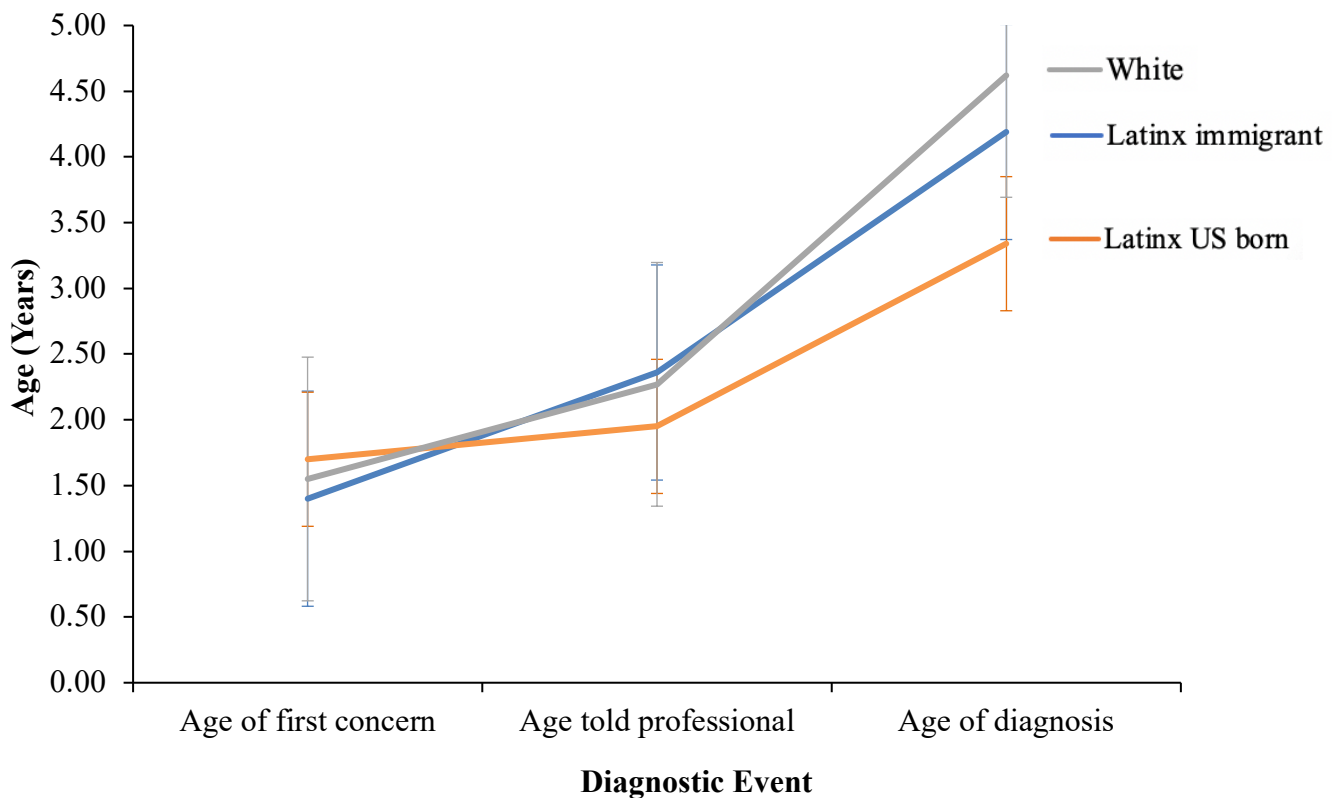


Figure 4. Child's Diagnostic Journey. ASD can be diagnosed at 2-3 years of age. Data points are means so error bars are included.

Professional's response presented in Figure 5 marked the amount of participants in each of the three groups who experienced this response when they first expressed concern. Significance tests were not conducted but there were differences in the professional's response toward participants between each group. Latinx immigrants were more likely to be referred to a specialist (58.3%) compared to Latinx U.S. born (47.4%) and White (37.3%). Latinx U.S. born were the group that was told the most that their child would "grow out of it" (36.8%) and that it was too early to tell if anything was wrong (52.6%). White participants were the least to be referred to a specialist (21.6%) and taken to conduct a developmental screener (21.6%). Overall, White participants seem to have been referred less, tested less, and most told child's development was okay.

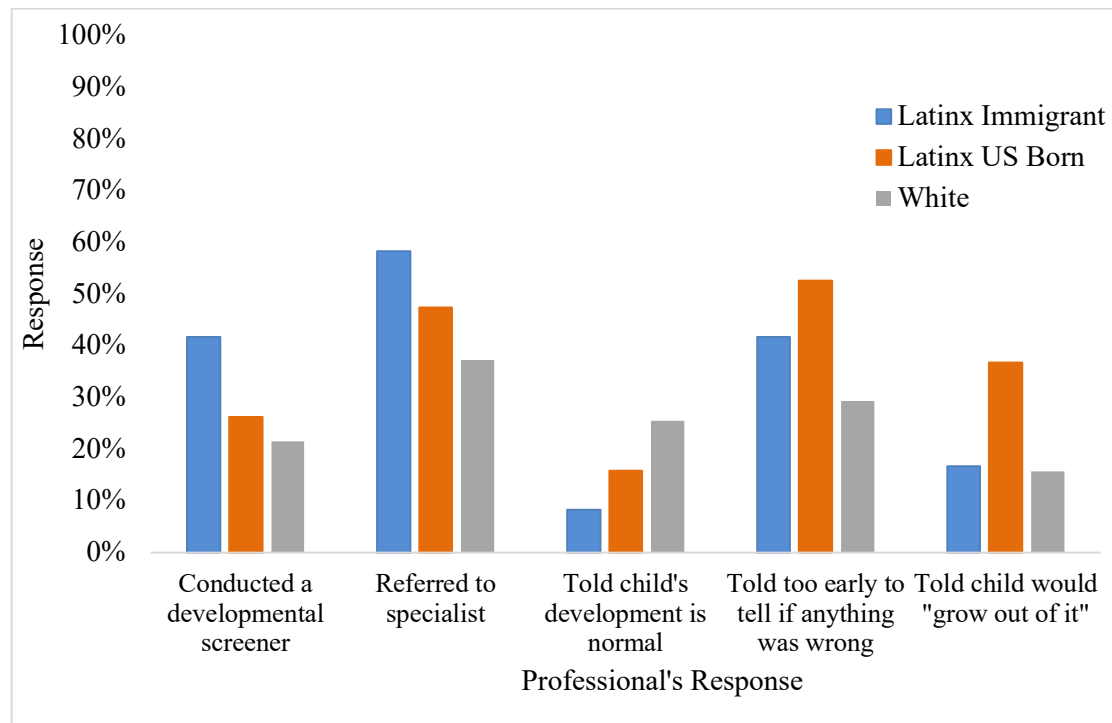


Figure 5. Professional's or doctor's response when parent's first expressed concern. This figure shows the percentage of participants that indicated professionals responded in each of these ways.

Further analyses also found differences between the groups during the diagnostic process in terms of gaining information, traveling to the appointments, and languages available. Latinx U.S. born participants had less difficulty getting information from professionals (57.9%) and understanding the health care system (36.8%) and experienced more discomfort at appointments (84.2%). White participants believed that language interpreters were more readily available (45.3%), had to travel less distance (15.1%), but most believed it was difficult to understand the health care system (50.9%), contrary to the hypothesis. Latinx immigrants similar to the hypothesis had to travel long distances (41.7%) but contrary to our hypothesis less thought it expensive to get an evaluation (8.3%).

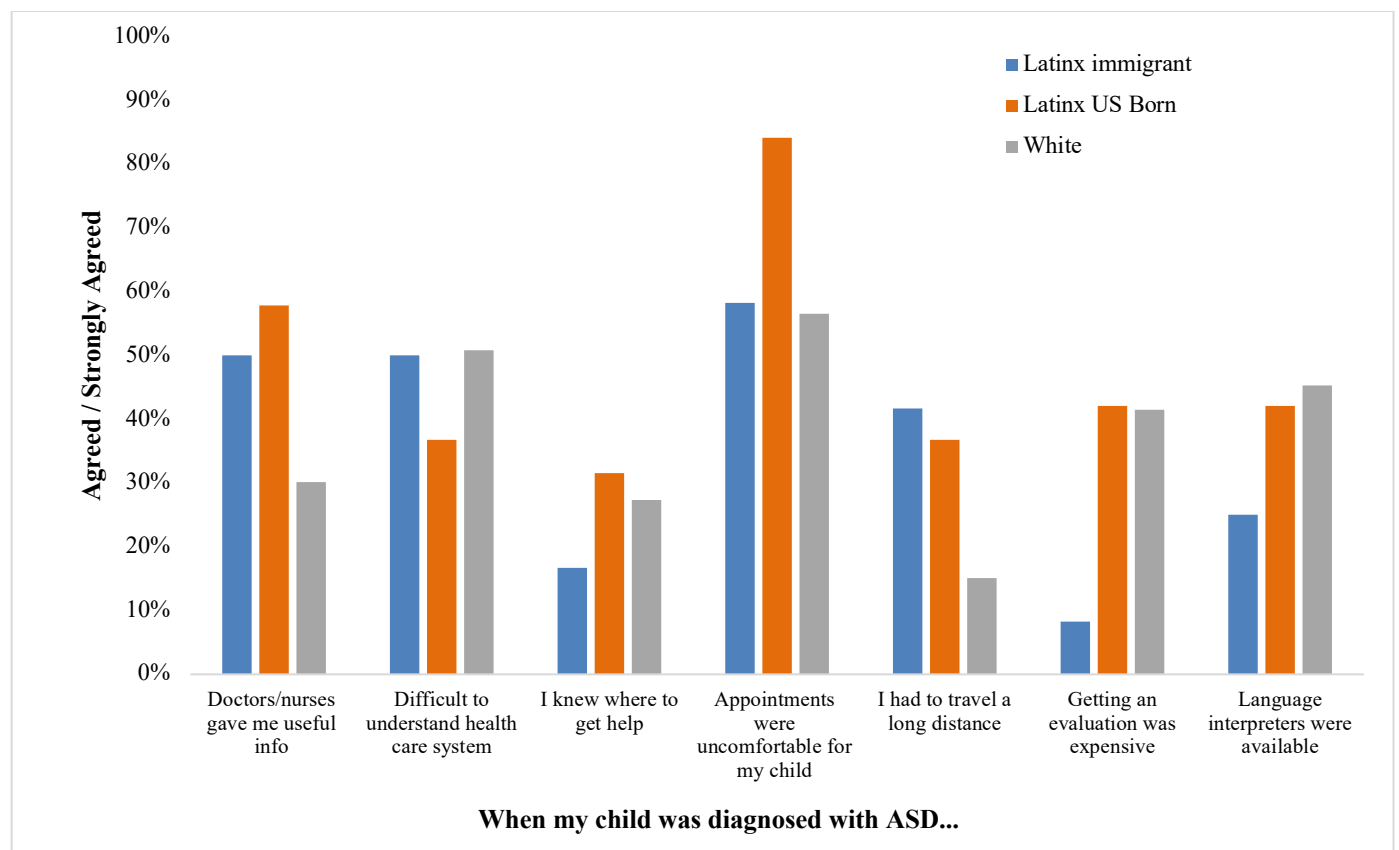


Figure 6. When a doctor diagnosed the child with ASD, participants were asked to think about whether they agreed or disagreed with the following statements.

Interventions, Services, and Resources

Results in this dependent variable category focused on applied behavior analysis (ABA) therapy, the most supported type of therapy for children with ASD. As seen on Figure 7 and contrary to the hypothesis, Latinx immigrants received early intervention services the most (80%) but felt that their therapy needs were met the least (27.3%). Latinx U.S. born received the least amount of ABA (26.8%) but felt most of their therapy needs were being met (52.9%). White children, contrary to the hypothesis, least received early intervention services (66%) but most received ABA (54.7%). Latinx populations seemed to receive more services early in their child's diagnosis but less as they grew older.

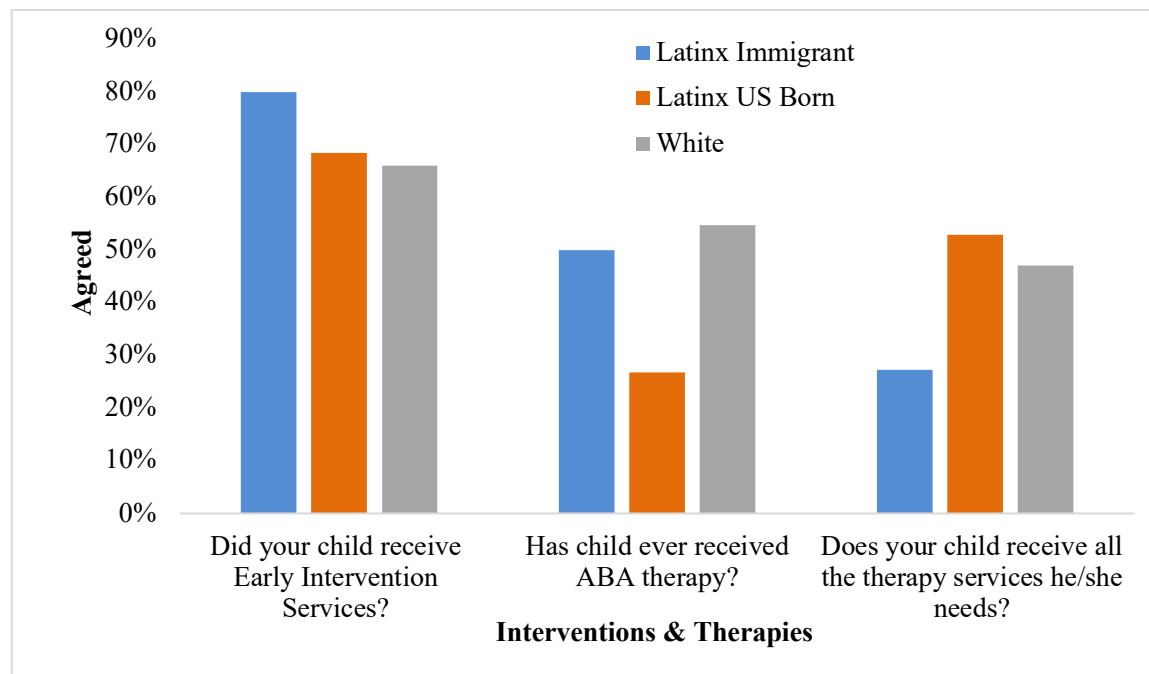


Figure 7. Percentages make up participant's somewhat agreeing or agreeing with the statements of receiving early intervention services and receiving all the therapy the child needs. ABA = applied behavior analysis.

Parent and Community Conceptualizations

Parent beliefs about the diagnostic process of ASD are presented in Figure 8. Latinx immigrants contrary to the hypothesis were least afraid of getting help because of legal issues (25%), were most able to access medical information (58.3%), and had the power to change their child’s ASD (33.3%). Similar to the hypothesis, they believed their child was a mystery (50%) and it was God’s plan for their child to have ASD (58.3%). In comparison, U.S. born Latinx least believed their child was a mystery (10.5%) but were somewhat afraid of legal issues their power to change their child’s ASD. White populations were the most afraid of legal issues (43.4%), less able to access medical information (49.1%), least had the power to change their child’s ASD (21.3%), and least believed it was God’s plan for their child to have ASD (19.7%).

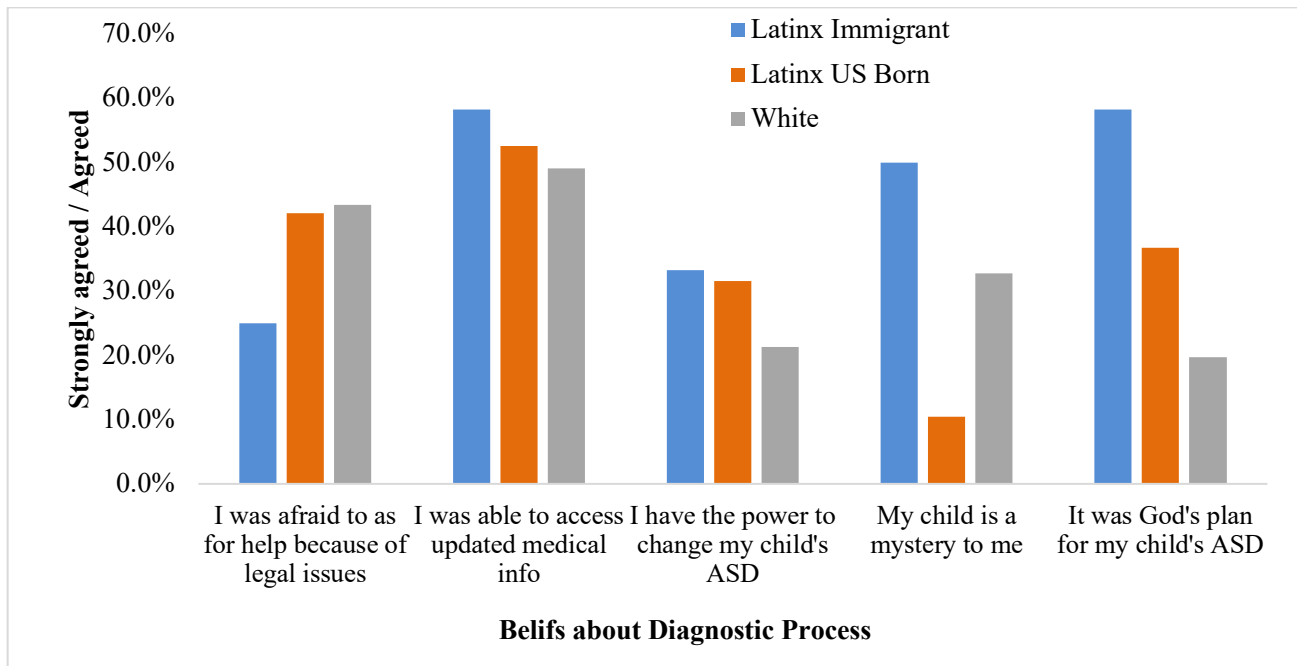


Figure 8. Beliefs about the diagnostic process of ASD.

Parent and community beliefs were also assessed. Figure 9 shows that U.S. born Latinx had the most negative conceptualizations about ASD (grow out of it: 62.5%, believed it only

happened in the U.S.: 44.4%, and were fearful of the future: 84.2%), but most understood their child’s strengths and challenges (89.5%). White parents were also very fearful of the future (82%) and most believed their child’s problems were caused by speaking a different language (45.3%), contrary to the hypothesis. Contrary to our hypothesis, Latinx immigrants least believed that their child’s problems were caused by speaking a different language (25%) and that ASD only occurred in the U.S. (25%).

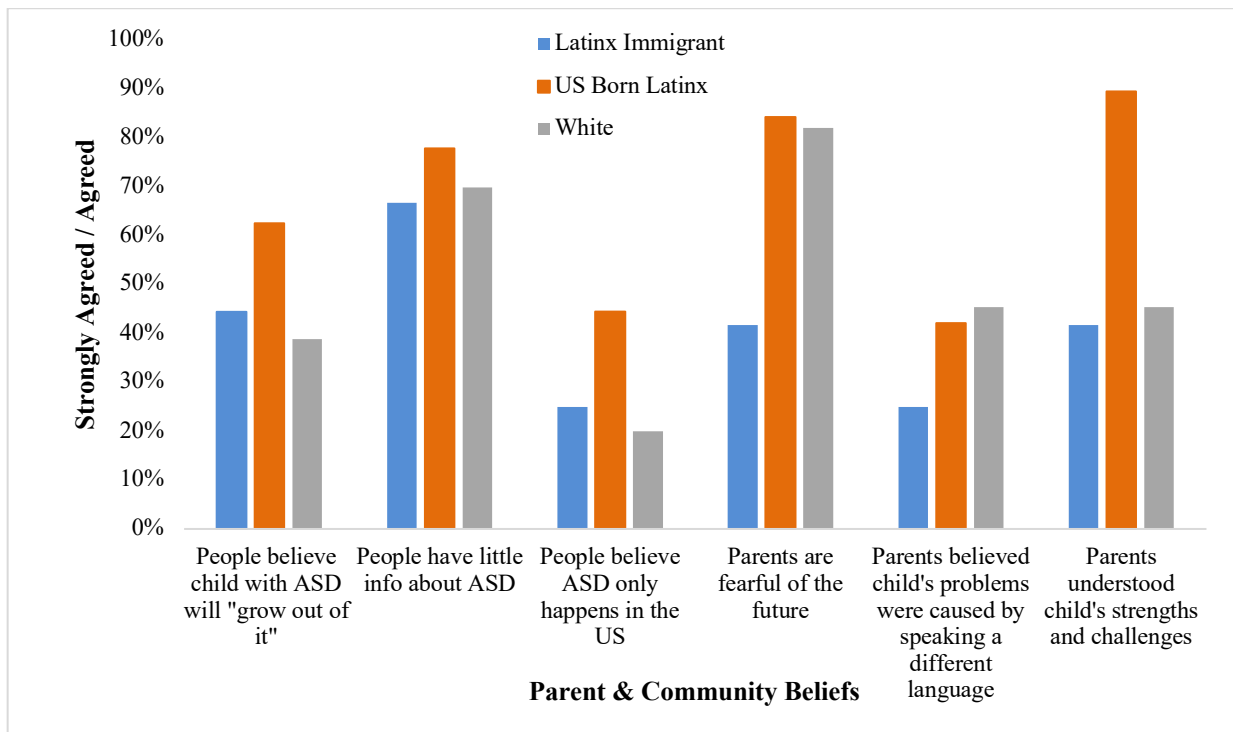


Figure 9. These results are about the views that parents and the participant’s community have about ASD. The community was defined as people the participants and their child see or talk with often. This figure shows the percentage of participants that agreed or strongly agreed with the statements.

DISCUSSION

Contrary to the hypothesis, results suggest that U.S. born Latinx were the ethnic group with the most differences. Results suggested there are differences linked to ethnicity in the diagnostic process, interventions and resources, and conceptualizations of ASD. Results suggest differences rather than disparities because disparities were defined as differences in health that adversely affect socially disadvantaged groups according to population characteristics such as race, religion, wealth, and ethnicity (Braveman et al., 2011). The differences found, however, were not always adversely affecting the group such as in the diagnostic process, therefore were not suggesting these marginalized groups had worse health outcomes. Overall, U.S. born Latinx had the most differences in the diagnostic process, interventions and resources, and conceptualization dependent variable categories.

Participant Demographics

The participant demographics of caregivers and child with ASD showed results that both supported and contradicted past research and the hypothesis. Age demographics, income, and education level, although significantly different between groups, supported research reflecting that White caregivers tended to be older, have increased income, and more education than Latinx populations. There was only a difference however in terms of Medicaid insurance between Latinx immigrants and White groups. In relation to income, Latinx immigrant and White groups had the most finances to help account for their child's health needs. This could influence the amount of interventions, therapy, and resources these families have access to. Contrary to past research suggesting that Latinx children diagnosed with ASD had a more severe diagnosis, results suggested that there was no difference in child support needs, meaning that diagnosed Latinx children did require more significant support than Whites. In other words, the children

that participated in our research had similar levels of ASD severity. Inquiring about level of severity in this survey also allowed for parents to identify their child on the autism spectrum based on DSM-V diagnostic criteria.

The Diagnostic Process

Contrary to past studies, there was no significant difference in the diagnostic journey of children with ASD in Texas between ethnicities. The results that were closest to being significant was the diagnostic journey of U.S. born Latinx in the age of diagnosis. U.S. born Latinx were diagnosed earlier than all other groups and showed the fastest process, while the slowest journey was taken by White children. Latinx immigrants also most identified with a positive professional response when expressing first concerns. They received more developmental screeners and referrals to specialists while being told less that their child's development was normal or that it was too early to tell. White participants received the least amount of referrals and received more negative professional responses. In agreement of past studies, Latinx immigrants identified having less language interpreters but U.S. born Latinx more strongly agreed that appointments were uncomfortable for their child. Results could also suggest that White participants had overall a harder time in the diagnostic journey because they had more difficulty gaining access to information from professionals and understanding it. All three groups, however, did have difficulty understanding the health care system, knowing where to get help, and had to travel long distances for evaluations.

Interventions, Services, and Resources

Although other medications and therapies were evaluated in the surveys, results focus on ABA therapy and early interventions. Results, contrary to past research, suggest that the ethnic group that had less access ABA therapies and did not receive all the therapy services the child

needed are the U.S. born Latinx participants. They were however, the group that felt most satisfied with the amount of therapy services their child was receiving. White participants were actually less likely to receive early intervention than the other groups but not significantly less likely. Latinx immigrants made most use of early intervention services but least received all the therapy they felt they needed. The overall results identified that Latinx immigrants seemed to make the most use of early intervention services but as children grew, they had less access to ABA. White children, on the other hand, had less access to early intervention services but gained more access to ABA as children grew.

Parent and Community Conceptualizations

Parent and community conceptualizations were largely assessed because they provided insight into the differences of beliefs between ethnicities and the role nativity and culture can play. Beliefs concerned “growing out of ASD,” ASD only being present in the U.S., being fearful of the future, and the role language played in the ASD diagnosis. Overall, U.S. born Latinx were the group to have to most negative conceptualizations about ASD, but also most understood their child’s strengths and challenges. Contrary to our hypothesis, Latinx immigrants were less fearful about the future, believed more strongly in God’s plan, but identified their child as being more of a mystery. All three groups somewhat believed they had the power to change their child. Another result was that Latinx immigrants were the least likely to agree that their child’s problems stemmed from speaking a language other than English at home; White participants were the group to most believe legality played a role in their seek for help. U.S. born Latinx were the group of participants that identified their community as having overall the most negative beliefs. Despite previous research identifying Latinx immigrants as having the most

negative community and parent conceptualizations, U.S. born Latinx participants resulted in having more negative views.

Implications

Knowledge of these differences or further disparities can help health care services improve confusing diagnostic processes, provide more bilingual initiatives, and ensure that all ethnic groups in Texas have equal access to services to further the developmental outcome of their children.

Limitations and future directions

The limitations of this study pertained to the sample and size. Failure to find main effects between ethnicities could be due to the Texas specific population for the survey. Despite the ethnic and cultural diversity in Texas, there may not be enough variability between families to suggest a significant difference in prevalence, resources, and beliefs. Additionally, the population could not have been as representative of the Texas children population which is made of 50% of Hispanics and 33% White (Lee, Deviney & La Sohn, 2016). Furthermore, only 84 participants results were used in this study, which limited the number of participants in each ethnic group. This study was also had selection bias. The Latinx participants in this study were recruited from a community outreach and support program that aids Latinx families in their process throughout ASD. These participants could have had more access to information and services and could have been more knowledgeable about ASD.

The results from this research suggest that there are differences associated with Latinx populations who were born in the U.S. rather than having immigrated to the U.S. later in life but further investigation is needed to continue evaluating the role of nativity and ethnicity plays. Further directions should include collecting a larger pool of participants to be able to conduct

significance testing. Researchers could also further the study by creating a survey aimed at participants in Texas without a child with ASD. Despite the ethnic and cultural diversity in Texas, there may not be enough variability between families to suggest a significant difference in prevalence, resources, and beliefs. Increasing the distribution of the survey to different states throughout the United States would be useful to gain more insight into differences in ethnicities.

References

- Angell, A. M., Empey, A., & Zuckerman, K. E. (2018). A Review of Diagnosis and Service Disparities Among Children with Autism from Racial and Ethnic Minority Groups in the United States. *International Review of Research in Developmental Disabilities*, *55*, 145–180. doi: 10.1016/bs.irrdd.2018.08.003
- Arcia E., Reyes-Blanes M.E., & Vazquez-Montilla, E. (2000). Constructions and Reconstructions: Latino Parents' Values for Children. *Journal of Child and Family Studies*. *9*(3):333, 333–350
- Autism Spectrum Disorder. (2018, March). Retrieved October 3, 2019, from <https://www.nimh.nih.gov/health/topics/autism-spectrum-disorders-asd/index.shtml>.
- Baio, J., Wiggins, L., Christensen, D.L., Maenner, M. J., Daniels, J., Warren, Z., ... Dowling, N.F. (2018). Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2014. *MMWR Surveill Summ* 2018;67(No. SS-6):1–23.
- Becerra, T. A., Ehrenstein, O. S. V., Heck, J. E., Olsen, J., Arah, O. A., Jeste, S. S., ... Ritz, B. (2014). Autism Spectrum Disorders and Race, Ethnicity, and Nativity: A Population-Based Study. *Pediatrics*, *134*(1). doi: 10.1542/peds.2013-3928
- Braveman, P. A., Kumanyika, S., Fielding, J., Laveist, T., Borrell, L. N., Manderscheid, R., & Troutman, A. (2011). Health Disparities and Health Equity: The Issue Is Justice. *American Journal of Public Health*, *101*(S1). doi: 10.2105/ajph.2010.300062
- Donvan, J., & Zucker, C. (2017). *In a different key: the story of autism*. New York: Broadway Books.

- Dubay, M., Watson, L. R., & Zhang, W. (2017). In Search of Culturally Appropriate Autism Interventions: Perspectives of Latino Caregivers. *Journal of Autism and Developmental Disorders, 48*(5), 1623–1639. doi: 10.1007/s10803-017-3394-8
- Ijalba, E. (2016). Hispanic Immigrant Mothers of Young Children With Autism Spectrum Disorders: How Do They Understand and Cope With Autism? *American Journal of Speech-Language Pathology, 25*(2), 200–213. doi: 10.1044/2015_ajslp-13-0017
- Lee, J., Deviney, F., & La Sohn, B. (2016). *State of Texas Children 2016* (pp. 1–38). Center for Public Policy Priorities.
- Magaña, S., Parish, S. L., Rose, R. A., Timberlake, M., & Swaine, J. G. (2012). Racial and Ethnic Disparities in Quality of Health Care Among Children with Autism and Other Developmental Disabilities. *Intellectual and Developmental Disabilities, 50*(4), 287–299. doi: 10.1352/1934-9556-50.4.287
- Mandell, D. S., Listerud, J., Levy, S. E., & Pinto-Martin, J. A. (2002). Race Differences in the Age at Diagnosis Among Medicaid-Eligible Children with Autism. *Journal of the American Academy of Child & Adolescent Psychiatry, 41*(12), 1447–1453. doi: 10.1097/00004583-200212000-00016
- Pedersen, A., Pettygrove, S., Meaney, F.J., Mancilla, K., Gotschall, K., Kessler, D. B., Grebe, T.A., & Cunniff, C. (2012) Prevalence of Autism Spectrum Disorders in Hispanic and Non-Hispanic White Children. *Pediatrics, 129*(3). doi: 10.1542/peds.2011-1145d
- Racial and Ethnic Identity. (2019). *American Psychological Association*. Retrieved from <https://apastyle.apa.org/style-grammar-guidelines/bias-free-language/racial-ethnic-minorities>.

Simpson, D. E., Hanley, J. J., & Quinn, G. (2002). *History of Autism Blame*. Retrieved from <http://archive.pov.org/refrigeratormothers/fridge/>

Texas Council on Autism and Pervasive Developmental Disorders. (2016). *The Texas Council on Autism and Pervasive Developmental Disorders: 2016 Report*. Retrieved from https://hhs.texas.gov/sites/default/files//texas-council-autism-pervasive-dev-disorders-2016_0.pdf

Zuckerman, K. E., Lindly, O. J., Reyes, N. M., Chavez, A. E., Macias, K., Smith, K. N., & Reynolds, A. (2017). Disparities in Diagnosis and Treatment of Autism in Latino and Non-Latino White Families. *Pediatrics*, *139*(5). doi: 10.1542/peds.2016-3010

Zuckerman, K. E., Sinche, B., Cobian, M., Cervantes, M., Mejia, A., Becker, T., & Nicolaidis, C. (2014). Conceptualization of Autism in the Latino Community and its Relationship with Early Diagnosis. *Journal of Developmental & Behavioral Pediatrics*, *35*(8), 522–532. doi: 10.1097/dbp.0000000000000091

Appendices

Appendix A:

Identifying Needs Among Texan Children with Autism Spectrum Disorder

Brochure and Link

<https://goo.gl/CppLw8>