Disparities in Diagnosis and Treatment of Autism in Latino and Non-Latino White Families

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abstract

OBJECTIVES: To compare barriers to autism spectrum disorder (ASD) diagnosis and current ASD-related service use among non-Latino white (NLW) families and Latino families with English proficiency (L-EP) or limited English proficiency (L-LEP).

METHODS: We conducted a mixed-mode survey of families of children with confirmed ASD seen at specialty clinics in 3 United States cities. Bivariate and multivariate analyses compared barriers to ASD diagnosis, current service use, and unmet therapy need among NLW, L-EP, and L-LEP families.

RESULTS: Overall, barriers to ASD diagnosis were prevalent: families (*n* = 352) experienced a mean of 8 of 15 barriers to ASD diagnosis. The most prevalent barriers overall were "stress of diagnostic process," "parent knowledge about ASD," and "understanding medical system." Compared with NLW families, L-LEP families were more likely to experience barriers related to knowledge about ASD and trust in providers. Children in L-LEP families also had fewer current therapy hours and more unmet therapy needs than children in NLW families. L-EP families' barriers and treatment services use profile was more similar to NLW than to L-LEP families.

CONCLUSIONS: English proficiency was an important marker for barriers to ASD diagnosis and treatment in Latinos. Increasing ASD-related knowledge and provider trust may decrease disparities in the diagnosis and treatment of ASD among US Latinos.

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WHAT'S KNOWN ON THIS SUBJECT: Racial/ethnic disparities exist in early identification and treatment of autism spectrum disorder (ASD), particularly among Latino children. Although the pervasiveness of these disparities is documented, reasons for these disparities have not been assessed from a family perspective.

WHAT THIS STUDY ADDS: Children in Latino families with parental limited English proficiency experienced different diagnostic barriers, used less ASD treatment, and had more unmet ASD therapy needs than children in English-proficient Latino families or children in non-Latino white families.

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ARTICLE

An estimated 1 in 68 US children has autism spectrum disorder (ASD).[1] Evidence suggests that prompt ASD diagnosis and treatment improves long-term developmental[2,3] and family[4] outcomes. However, multiple studies highlight racial/ethnic disparities in ASD care.[5–7] Disparities are especially notable among US Latino children: ASD is diagnosed less often among Latino compared with non-Latino white (NLW) children.[1] Latino children are less often diagnosed before age 4[8] and are diagnosed later than NLW children with similar clinical presentations.[9] When Latinos are diagnosed, they are more likely to have severe presentations, such as comorbid intellectual disability.[5,10] After diagnosis, Latinos with ASD receive fewer evidence-based treatments and less medical specialty care than NLWs.[6,11]

Few resources address the reasons for Latino/NLW disparities in ASD care. In *Unequal Treatment*,[12] the Institute of Medicine's 2003 report, health care disparities are described as multifactorial in nature: both provider/health care system and patient/family factors play roles. Similar factors may influence ASD disparities: for instance, pediatric providers are less likely to screen Spanish versus English speakers for ASD and feel less comfortable identifying ASD risk when families speak Spanish.[13] Latinos with Spanish as their primary language receive less family-centered care for ASD than NLW families[5,6] and are less likely to receive care consistent with families' values.[14] In addition, commonly used ASD screening[15] and diagnostic[16] tools may function differently when used with Latinos, making appropriate screening more difficult.

Less research has examined which patient and family factors contribute to ASD disparities. Maternal education and knowledge about ASD may mediate access to ASD care: families with higher maternal education and ASD knowledge have better access to ASD care regardless of ethnicity.[6] Latino parents may have less information about ASD generally[17,18] and limited knowledge about diagnostic/treatment resources[6] or how to access them.[19] Community disability stigma and skepticism regarding ASD diagnosis may mediate Latino/NLW disparities.[17] Child sociodemographic factors, such as public insurance status[5] or metropolitan residence,[20] may also impact access to care for children with ASD, although effects on Latinos have not been examined.

To our knowledge, no previous multisite studies have assessed barriers to ASD care among Latino versus NLW families with confirmed ASD. No studies have examined links between barriers experienced and subsequent treatment use. Although English proficiency is a sensitive marker of health care access for Latinos,[21] no studies have investigated its role in ASD disparities. Thus, we surveyed Latino and NLW families seeking ASD care to determine how barriers to ASD diagnosis differed by ethnicity and parental English proficiency. Among ethnicity/language groups, we sought to identify differences among ASD treatment types and intensity. Finally, we assessed whether barriers to ASD care were associated with disparities in services access among Latinos and NLW families.

METHODS

Study Sample and Design

In 2014–2015, we surveyed parents of Latino and NLW children seen at ASD clinics in Los Angeles, California; Denver, Colorado; and Portland, Oregon. Clinics were chosen because they were current or former members of the Autism Speaks Autism Treatment Network and thus had similar ASD diagnostic processes, and because the clinics had high Latino populations. The study enrolled families of children aged 2 to 10 years with an ASD diagnosis confirmed in the previous 5 years. A random sample of eligible medical records was selected at each site and stratified by race/ethnicity with the use of electronic medical record data, to ensure adequate Latino enrollment. Manual chart audits confirmed that ASD diagnosis included multidisciplinary evaluation and use of Autism Diagnostic Observational Schedule and *Diagnostic and Statistical Manual of Mental Disorders*, *Fourth Edition*, *Text Revision*, or *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition*, criteria.[22] Children in foster care, those with significant comorbid developmental disabilities, those whose families spoke neither English nor Spanish, or who did not identify as Latino or NLW were excluded. Eligible families (n = 489) were mailed an English or Spanish survey; families who did not return surveys were offered telephone survey administration by bilingual/bicultural interviewers. Of 489 participants contacted, 370 were surveyed for a composite response rate[23] of 76.2%. Families who did not indicate race/ethnicity (n = 7) on the survey and those with demographic characteristics outside of our eligibility criteria (n = 11) were subsequently excluded, yielding an analytic sample of 352 participants. Each institution's institutional review board approved the protocol. Consent was implied by survey completion.

Survey Development

Previously used and/or validated measures were used when possible. Demographic items were adapted from the 2009/2010 National Survey of Children with Special Health Care Needs[24] and the US Census American Community Survey.[25] Items on autism services were adapted from the 2011 Survey of Pathways to
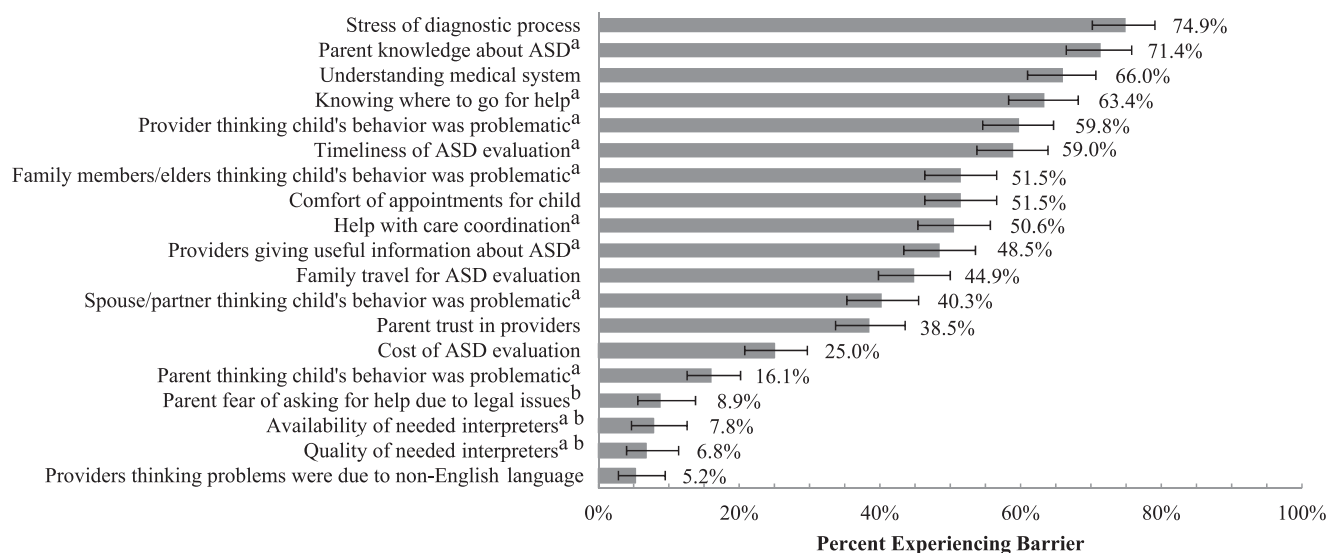
FIGURE 1
Overall prevalence of participants experiencing barriers to ASD care (*n* = 352). [a] Item was reverse coded. [b] Item was only assessed among Latinos.

Diagnosis and Services.[26] Because no validated family-reported measures of barriers to ASD care existed, a new survey measure was developed on the basis of previous qualitative research by our group.[17] We used English and Spanish cognitive interviews[27] with parents of children with ASD to iteratively refine item wording, clarify response options, and assess overall survey design. Autism Parent Advisory Committees at 2 sites provided additional feedback on survey wording. The Flesch-Kincaid Grade Level Test was used to adjust items to a sixth-grade reading level. The final survey consisted of 34 items assessing experiences of potential barriers to ASD diagnosis, current therapy use, beliefs about ASD, and demographic information.

Barriers to ASD Diagnosis

Fifteen items addressed barriers to ASD diagnosis (Fig 1). For each item, participants were asked to "think back about the period before a doctor diagnosed your child with ASD," and were presented with negatively and positively phrased statements (eg, "Before a doctor diagnosed my child with ASD it was difficult to trust doctors' or nurses' advice"). For each

statement, participants indicated agreement on a 4-part scale. Four additional items assessed barriers hypothesized as specific to Latinos, such as not speaking English as a primary language and experiencing legal issues. These 4 items included "does not apply" as a response option. A barrier was considered present if a family "somewhat or definitely" agreed with negatively phrased items or "somewhat or definitely disagreed" with positively phrased items; "does not apply" responses were considered equivalent to not experiencing the barrier. A count of the total number of barriers experienced by each family was constructed from the 15 barriers applicable to all families.

Current Treatment Service Use

Child's current treatment was assessed by using multiple items. A binary item assessed the presence of current Individualized Education Program or Individual Family Service Plan. Parents indicated specific ASD therapy services their child received currently and regularly. Parents then estimated total hours of weekly therapy. Pharmacologic and complementary and alternative medicine treatments for ASD were

also assessed. Unmet therapy needs (herein "unmet needs") were assessed by using a 2009/2010 National Survey of Children with Special Health Care Needs item[24] ("Does your child receive all the therapy service s/he needs?"), which parents rated on a 4-part scale.

Race, Ethnicity, and English Proficiency

Combined race/ethnicity and English proficiency ("ethnicity/language") was the primary independent variable. It was based on parent report by using items from the US Census American Community Survey.[25] Three mutually exclusive groups were defined: NLW, Latino English proficient (L-EP), and Latino limited English proficient (L-LEP). Latino ethnicity was determined if the parent reported his/her ethnicity and/or the child's ethnicity was "of Hispanic or Latino origin," regardless of racial category. NLW was determined if the parent reported (1) that his/her race and his/her child's race was white and (2) that both parent and child ethnicity was reported as non-Latino. Parental English proficiency was determined per federal guidelines[28] by using the item: "How well do you speak English?" Parents responding "very

TABLE 1 Study Sample Characteristics Overall and by Parent Ethnicity/Language

	Overall (*n* = 352)	NLW (*n* = 163)	L-EP (*n* = 95)	L-LEP (*n* = 94)
Overall, %		46.3	27.0	26.7
Parent/household characteristics				
Respondent's relationship to child, %				
Mother (*n* = 316)	89.3	86.5	89.4	96.8
Father (*n* = 27)	8.2	9.2	9.6	3.2
Other (*n* = 8)	2.5	4.3	1.1	0.0
Number of children per household (*n* = 346), mean ± SD	2.1 ± 1.1	2.0 ± 1.0	2.2 ± 1.24	2.4 ± 1.1
Number of children with ASD per household (*n* = 342), mean ± SD	1.1 ± 0.4	1.2 ± 0.5	1.1 ± 0.3	1.2 ± 0.6
Parent nativity				
Always lived in United States (*n* = 228), %	64.8	90.2	82.1	3.2
Lived outside the United States (*n* = 124), %	32.3	9.8	17.9	96.8
Years lived in United States, mean ± SD	17.2 ± 8.3	21.9 ± 13.0	22.4 ± 9.8	15.5 ± 6.3
Latino parent national origin/heritage, %				
Mexico (*n* = 110)	78.7	—	71.7	83.8
Other Latin American countries or Spain (*n* = 30)	21.3	—	28.3	16.3
Family structure, %				
Married or living with partner (*n* = 278)	79.3	80.4	77.9	78.5
Single (*n* = 32)	9.0	8.6	9.5	9.7
Other (*n* = 41)	11.7	11.0	12.6	11.8
Parent education (*n* = 345), mean ± SD, y	13.7 ± 3.9	15.0 ± 3.6	14.6 ± 3.0	10.4 ± 3.4
Median	14.0	15.0	14.0	10.5
Range	0–25	2–25	9–24	0–18
Parent employment				
Unemployed (*n* = 178), %	50.6	44.8	40.0	71.3
Employed (*n* = 174), %	49.4	55.2	60.0	28.7
Hours per week, mean ± SD	33.9 ± 12.6	33.4 ± 12.9	36.5 ± 12.6	31.0 ± 10.2
Child characteristics				
Child's age (*n* = 343), mean ± SD, y	5.8 ± 2.0	5.9 ± 2.1	5.8 ± 1.9	5.6 ± 2.0
Child's sex, %				
Male (*n* = 291)	84.0	78.9	84.0	91.4
Female (*n* = 57)	16.0	21.1	16.0	8.6
Child health insurance, %				
Public health insurance only (*n* = 210)	60.6	48.2	51.1	92.3
Any private health insurance (*n* = 137)	39.4	51.9	48.9	7.7
Child ASD severity, %				
Mild (*n* = 162)	47.1	50.3	47.9	40.7
Moderate or severe (*n* = 182)	52.8	49.7	52.1	59.3
Study site characteristics, %				
Site 1	31.1	53.6	22.7	23.6
Site 2	32.4	39.5	38.6	21.9
Site 3	36.5	46.1	23.3	33.6

—, not applicable.

well" were categorized as English proficient. Parents responding "well," "not well," or "not at all" were categorized as limited English proficient.

Covariates

Child-level covariates included factors known to modify ASD service access,[19,29] including child age, child sex, parent-reported ASD severity, and child health insurance type. Family-level covariates included the respondent's relationship to the child, parental educational attainment, family structure, parent employment status, and number of children in household.

Statistical Analyses

Descriptive statistics assessed participant characteristics (Table 1), frequency of barriers to ASD care (Fig 1), and receipt of ASD services (Fig 2). Each site's response characteristics were separately examined before pooling across sites.

Bivariate statistics were computed to compare proportions of L-LEP, L-EP, and NLW families experiencing each barrier and using each treatment.

Adjusted logistic regression was used to determine associations of ethnicity/language with (1) experiencing individual barriers, (2) using each treatment, and (3) experiencing unmet therapy needs (Tables 2 and 3). To determine the expected count of barriers for families of children with ASD according to their ethnicity/language, Poisson regression[30] was used given the dependent variable type (ie, a count with no negative values) and its distribution (ie, mean = 7.56 and variance = 7.29). Multinomial logistic regression was used to determine

ethnicity/language associations with weekly hours of therapy services.

To determine differences between L-LEP and L-EP families compared with NLW families on variables related to treatment use, while examining the effects of barriers experienced, we used multiple approaches. We fit a multinomial regression model to determine associations of weekly therapy hours with ethnicity/language and number of barriers experienced. To determine associations of unmet needs with ethnicity/language and barriers experienced, we fit an adjusted logistic regression model. We tested whether ethnicity/language modified associations between number of barriers experienced and likelihood of unmet needs.

To minimize type I error while reducing confounding, we used a stepwise backward elimination procedure to include covariates in all multivariable models for elimination ($\propto$ = 0.15) and addition ($\propto$ = 0.10). The covariate selection procedure included all child- and family-level covariates described above. Each multivariable model adjusted for study site to account for site-specific confounding. All analyses were performed in Stata 14.0 (StataCorp, College Station, TX). To account for multiple comparisons, we considered results statistically significant when P values were < .01; P values between .01 and .05 were considered of marginal significance.

RESULTS

Study Sample

Overall, 352 parents reported data on their family and child with ASD. Per the study design, approximately half of the respondents were NLW (46.3%). Latino participants were evenly divided between L-EP (27.0%) and L-LEP (26.7%). Sites were generally similar in child and
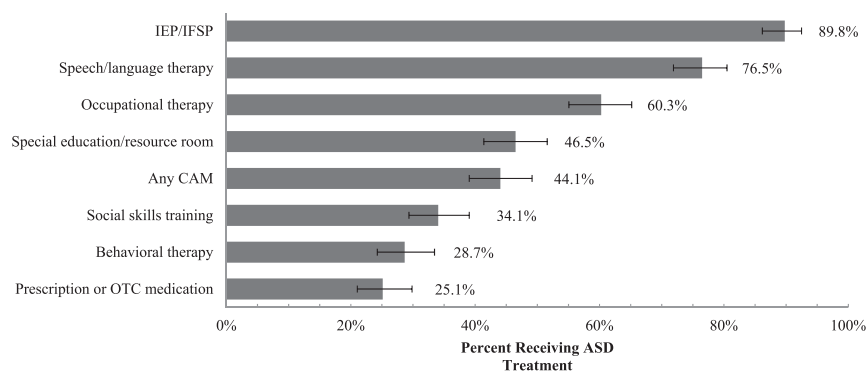
FIGURE 2
Overall prevalence of ASD treatments that participants received (n = 352). CAM, complementary and alternative medicine; IEP/IFSP, Individualized Education Program/Individual Family Service Plan; OTC, over-the-counter.

family characteristics; site 3 had more Latinos of Mexican origin and more unemployed parents compared with other sites. Compared with other ethnicity/language groups, L-LEP families were more likely to have a mother respondent, have more children per household, have lived outside the United States, have lower parental education, have the respondent be unemployed, and have their child with ASD be publicly insured only (Table 1).

Barriers to ASD Diagnosis

Families experienced a mean of 8 "somewhat" or "definite" barriers out of 15 barriers to ASD care. Nine barriers were experienced by >50% of families. "Stress of diagnostic process" (74.9%) was the most frequently reported barrier overall (Fig 1). Among barriers assessed in all families, being L-LEP versus NLW increased the expected number of barriers by 11%, but this association was not statistically significant (adjusted incidence rate ratio: 1.11; 95% confidence interval: 1.00–1.25; P = .057). The number of barriers was similar for L-EP and NLW families (adjusted incidence rate ratio: 1.02, 95% confidence interval: 0.92–1.12; P = .76).

The most common barrier among L-LEP and L-EP families was "parent knowledge about ASD" (85.1% and 72.3%, respectively). The most

common barrier among NLW families was "stress of diagnostic process" (78.4%). "Parent knowledge about ASD" and "parent trust in providers" were significantly more common among L-LEP than among NLW families. "Understanding the medical system" was marginally more common and "cost of ASD evaluation" was marginally less common among L-LEP (versus NLW) families. The only significant difference in specific barriers experienced between L-EP and NLW families was "stress of diagnostic process," which was less common for L-EP families.

None of the 4 barriers hypothesized as being specific to Latinos were as common as the more general 15 barriers. The most common Latino-specific barrier was "parent fear of asking for help due to legal issues." All Latino-specific barriers were more common for L-LEP than for L-EP families, with a large difference in found in "fear of asking for help due to legal issues" (16.0% vs 2.1%; Table 2).

ASD Treatments, Treatment Dose, and Unmet Treatment Needs

Overall, 95.7% of families reported currently using any of the treatments assessed. The most frequently used treatment was speech/language therapy (76.5%). A total of 28.7% families reported using behavioral therapy, including applied behavior

TABLE 2 Bivariate and Multivariable Associations of Ethnicity/Language With Barriers to ASD Care

Types of barriers to ASD care	% (95% CI)			aOR (95% CI)	
	NLW (n = 163)	L-EP (n = 95)	L-LEP (n = 94)	L-EP Versus NLW	L-LEP Versus NLW
Parent thinking child's behavior was problematic[a]	17.3 (12.2–23.9)	16.8 (10.5–25.8)	11.7 (6.6–20.0)	0.88 (0.44–1.78)	0.64 (0.30–1.37)
Spouse/partner thinking child's behavior was problematic[a]	35.5 (28.3–43.4)	43.0 (33.3–53.2)	42.9 (33.0–53.3)	1.37 (0.78–2.41)	1.60 (0.90–2.83)
Provider thinking child's behavior was problematic[a]	57.5 (49.7–65.0)	69.5 (59.4–78.0)	50.0 (39.8–60.2)	1.69 (0.94–3.01)	1.15 (0.60–2.20)
Family members/elders thinking child's behavior was problematic[a]	52.5 (44.7–60.2)	49.5 (39.5–59.5)	50.0 (39.8–60.2)	0.84 (0.47–1.50)	1.26 (0.66–2.43)
Stress of diagnostic process	78.4 (71.4–84.1)	64.2 (54.0–73.3)	81.9 (72.7–88.5)	0.43 (0.24–0.77)*	1.19 (0.54–2.63)
Parent knowledge about ASD[a]	63.8 (56.1–70.9)	72.3 (62.4–80.5)	85.1 (76.3–91.0)	1.55 (0.86–2.79)	3.82 (1.83–7.98)**
Providers giving useful information about ASD[a]	51.5 (43.8–59.2)	51.6 (41.5–61.5)	39.4 (30.0–49.6)	1.04 (0.60–1.77)	0.96 (0.50–1.85)
Understanding medical system	64.0 (56.2–71.1)	61.1 (50.8–70.4)	74.2 (64.3–82.1)	0.82 (0.48–1.43)	2.17 (1.12–4.21)***
Parents trusting providers	34.4 (27.4–42.0)	28.4 (20.2–38.4)	58.1 (47.8–67.7)	0.72 (0.40–1.31)	2.45 (1.42–4.25)**
Parent knowing where to go for help[a]	61.4 (53.6–68.6)	58.8 (48.3–68.1)	75.3 (65.4–83.0)	0.77 (0.44–1.33)	1.69 (0.76–3.73)
Help with care coordination[a]	49.4 (41.7–57.1)	52.6 (42.5–62.5)	51.6 (41.4–61.7)	1.11 (0.66–1.88)	1.25 (0.73–2.17)
Comfort of appointments for child	50.9 (43.2–58.6)	54.7 (44.6–64.5)	54.4 (44.0–64.3)	1.07 (0.61–1.89)	0.74 (0.41–1.50)
Timeliness of ASD evaluation[a]	60.5 (52.7–67.8)	59.6 (49.3–69.1)	56.5 (46.2–66.3)	1.00 (0.59–1.71)	0.82 (0.48–1.41)
Family travel for ASD evaluation	42.3 (34.9–50.1)	53.2 (43.0–63.1)	42.9 (33.0–53.3)	1.51 (0.90–2.54)	0.98 (0.58–1.66)
Cost of ASD evaluation	31.5 (24.8–39.1)	26.6 (18.6–36.5)	10.8 (5.9–18.9)	0.85 (0.47–1.54)	0.44 (0.20–0.99)***
Availability of needed interpreters[a,b,c]	—	4.2 (1.6–10.8)	11.7 (6.6–20.0)	—	—
Quality of needed interpreters[a,b,c]	—	5.3 (2.2–12.1)	8.5 (4.3–16.2)	—	—
Providers thinking problems were due to non-English family language[b,c]	—	4.3 (1.6–10.9)	6.4 (2.9–13.6)	—	—
Parent fear of asking for help due to legal issues[b,c]	—	2.1 (0.5–8.2)	16.0 (9.8–24.9)	—	—
"Somewhat or definite" barriers[d]	7.5 ± 2.9[e]	7.4 ± 2.7[e]	7.7 ± 2.4[e]	1.01 (0.92–1.12)[f]	1.11 (1.00–1.25)***[f]

A barrier was considered present if a parent responded "somewhat yes" or "definitely yes" to negatively phrased barriers or "somewhat no" or "definitely no" to positively phrased barriers. Model covariates included child age, child sex, ASD severity, child health insurance type, respondent's relationship to child, parental education, family structure, parent employment status, and number of children in household. A backward elimination process was used to construct each model, with variables maintaining $P < .10$ included in the final model. aOR, adjusted odds ratio; CI, confidence interval; —, value was not computed because barrier variables excluded NLW participants.

[a] Item was reverse coded for data analysis.

[b] Families who answered "not applicable," "definitely disagree," and "disagree" were considered to not endorse the barrier, whereas those who responded with "agree," or "definitely agree" were considered to endorse the barrier.

[c] Only assessed for Latinos.

[d] Excludes barriers only assessed in Latinos.

[e] mean ± SD

[f] Value represents an incidence rate ratio; excludes barriers only assessed in Latinos.

* $P < .01$.

** $P < .001$.

*** $P < .05$.

TABLE 3 Bivariate and Multivariable Associations of Ethnicity/Language With Current Services Use

	% (95% CI)			Adjusted Ratio (95% CI)[a]	
	NLW (n = 163)	L-EP (n = 95)	L-LEP (n = 94)	L-EP versus NLW	L-LEP versus NLW
Treatments used for ASD[b]				Adjusted OR (95% CI)[c]	
Speech/language therapy	71.8 (64.3–78.2)	81.1 (71.8–87.8)	79.8 (70.4–86.8)	1.48 (0.76–2.90)	1.25 (0.65–2.39)
Social skills training	39.9 (32.6–47.6)	27.4 (19.3–37.3)	30.9 (22.3–41.0)	0.53 (0.29–0.97)***	1.02 (0.54–1.93)
Occupational therapy	57.7 (49.9–65.1)	62.1 (51.9–71.3)	60.6 (50.4–70.1)	1.11 (0.63–1.94)	1.10 (0.64–1.87)
Behavioral therapy[d]	33.7 (26.9–41.4)	33.7 (24.9–43.8)	14.9 (9.0–23.7)	0.87 (0.47–1.61)	0.63 (0.27–1.50)
Special education/resource room	50.3 (42.6–58.0)	42.1 (32.5–52.3)	46.8 (36.9–57.0)	0.60 (0.34–1.04)	0.72 (0.39–1.35)
Any CAM	50.3 (42.6–58.0)	42.1 (32.5–52.3)	38.30 (29.0–48.6)	0.81 (0.46–1.40)	0.57 (0.33–0.99)***
Prescription or OTC meds	25.8 (19.6–33.1)	29.5 (21.1–39.5)	20.2 (13.2–29.6)	1.15 (0.59–2.25)	0.81 (0.39–1.69)
IEP/IFSP	88.2 (82.2–92.4)	94.7 (87.9–97.8)	88.9 (80.5–94.0)	0.46 (0.16–1.30)	2.21 (0.72–6.80)
Unmet need for therapy	40.9 (33.5–48.7)	51.6 (41.5–61.5)	60.4 (50.0–70.0)	1.55 (0.89–2.69)	2.12 (1.21–3.70)*
Therapy dose				Adjusted RR Ratio (95% CI)[e]	
<1 h or no weekly therapy	12.4 (8.1–18.5)	13.7 (8.1–22.2)	26.1 (18.0–36.4)	1.61 (0.61–4.25)	4.51 (1.73–11.77)*
1–10 h weekly therapy	64.0 (56.2–71.1)	63.2 (53.0–72.3)	59.1 (48.5–68.9)	1.39 (0.71–2.72)	1.73 (0.80–3.73)
≥11 h weekly therapy	23.6 (17.6–30.8)	23.2 (15.7–32.8)	14.8 (8.7–23.9)	1.00	1.00

CAM, complementary and alternative medicine; CI, confidence interval; IEP/IFSP, Individual Education Program/Individual Family Service Plan; OR, odds ratio; OTC, over-the-counter; RR, relative risk.

[a] Model covariates included child age, child sex, ASD severity, child health insurance type, respondent's relationship to child, parental education, family structure, parent employment status, and number of children in household. A backward elimination process was used to construct each model, with variables maintaining $P < .10$ included in the final model.

[b] Child was considered to be receiving therapy if the therapy was delivered currently on a regular basis.

[c] The values in this column represent adjusted ORs for all ASD treatments, with the referent being if the child did not receive the respective treatment.

[d] Behavioral therapy includes applied behavioral analysis and "other behavioral therapies."

[e] The values in this column represent adjusted RR ratios estimated from a multinomial logistic regression model in which ≥11 therapy hours per week was the referent category.

* $P < .01$.

*** $P < .05$.

TABLE 4 Associations of Barriers to ASD Diagnosis and Treatment With Services Use

	Multinomial Logistic Model (n = 328)		Logistic Model (n = 337)
	1–10 Hours of Therapy per Week Versus ≥11 Hours of Therapy, Adjusted RR Ratio (95% CI)	<1 or No Hours of Therapy per Week Versus ≥11 Hours of Therapy, Adjusted RR Ratio (95% CI)	Adjusted OR (95% CI) of Having Any Unmet Therapy Need Versus No Unmet Therapy Need
Number of barriers experienced	0.95 (0.86–1.05)	0.95 (0.83–1.09)	1.22 (1.11–1.33)
P	.32	.48	<.001
Parent Latino ethnicity			
NLW	1.00	1.00	1.00
L-EP	1.44 (0.74–2.80)	1.55 (0.60–4.02)	1.50 (0.87–2.59)
P	.29	.36	.15
L-LEP	1.82 (0.84–3.94)	4.59 (1.76–11.97)	1.95 (1.12–3.39)
P	.13	.002	.02

All models included number of barriers, parent ethnicity, and site. A stepwise backward elimination procedure was used to select the remaining child and/or family covariates for each multivariable model. CI, confidence interval; OR, odds ratio; RR, relative risk.

analysis; 89.8% of families reported their child had an Individualized Education Program/Individual Family Service Plan (Fig 2). There were few differences in type of therapy by ethnicity/language; however, L-LEP families were less likely to use complementary and alternative medicine and L-EP families were less likely to use social skills training (versus NLW families) (Table 3).

Most children received 1 to 10 hours of weekly therapy for ASD. Compared with NLW children, L-LEP children were more likely to have <1 or no hours of weekly therapy versus ≥11 weekly therapy hours. There were no significant differences in therapy dose between L-EP and NLW children. Unmet need for therapy was experienced by the majority of families, but was significantly more likely among L-LEP versus NLW families (Table 3).

Associations of Ethnicity/Language With Barriers, Therapy Dose, and Unmet Needs

When the number of barriers to ASD care was held constant in multivariable models, L-LEP children were still less likely to have any treatment hours for ASD (<1 or no hours) compared with NLW children. Similarly, L-LEP families were more likely than NLW families to have unmet needs after adjustment for number of barriers (Table 4). This relationship is shown in Supplemental Fig 3: as the number of barriers to ASD care increases, Latinos (L-EP and L-LEP) were increasingly more likely than NLW families to have unmet needs.

DISCUSSION

This study assessed racial/ethnic and language differences in barriers to care and service use in a multisite sample of children with confirmed ASD. The study found that although all families experienced significant barriers to ASD care, L-LEP families experienced some barriers disproportionately, had the highest levels of unmet therapy needs, and the lowest weekly therapy hours. Higher numbers of barriers to care were associated with more unmet needs, particularly among Latinos. Study findings indicate the L-LEP families especially struggle in accessing ASD diagnostic and treatment resources.

The most frequent barrier for L-LEP families, and the barrier differing most from NLW families, was "parent knowledge about ASD," which was experienced by >85% of L-LEPs. The finding confirms qualitative work revealing a low awareness of ASD and its symptoms in Spanish-speaking Latino communities,[17,18] even as overall ASD awareness has become widespread. Similarly, "parent knowing where to go for help" was slightly more common among L-LEP compared with NLW families, suggesting the information about the ASD diagnostic process is important for L-LEP families. The study found significant differences in therapy hours and unmet needs by ethnicity/language, suggesting access to all types of therapy services remains a significant challenge for L-LEP families.

It is notable that even after adjustment for number of barriers, L-LEP children were still less likely to receive therapy. In addition, as the number of barriers increased, unmet needs affected Latinos disproportionately. Findings suggest that although more barriers are associated with unmet therapy needs for Latinos, they do not fully explain disparities in service use. Some barriers studied may be more important than others as mediators of access to care.

Findings are also notable for barriers that did not differ between NLW families and Latinos. No ethnicity/language differences were found in rates of caregivers or providers who thought a child's early behavior was problematic, even though this is sometimes cited as a reason Latinos delay seeking ASD care.[31,32] Likewise, logistical (eg, travel) and economic (eg, cost) barriers were less common than knowledge gaps about ASD and the diagnostic process, and factors such as interpreting services and legal concerns played relatively minor roles. Although these factors are often cited as deterrents to ASD care in minorities, our findings suggest that factors such as ASD knowledge and health care system navigability may be more important intervention targets. More broadly, 9 of 15 barriers studied were experienced by at least 50% of the sample, and mean number of barriers experienced was nearly 8. Thus, whereas aspects of ASD health care access were challenging for L-LEP families, many challenges were shared by most families of children with ASD. Because several of the more disparate barriers were prevalent in all groups, targeting these barriers might both improve overall care quality and reduce disparities.

Findings suggest opportunities for remediation of disparities in access to ASD services. Because "parent knowledge about ASD" and "understanding the medical system" showed significant racial/ethnic differences, campaigns and community awareness activities in Latino communities might increase knowledge about ASD and reduce disparities. To be effective, campaigns should use simple, clear messaging about ASD and steps parents should take to access care. Given "trust in providers" was also more problematic for L-LEP compared with NLW families, messages should be delivered in culturally competent ways or via trusted brokers (eg, community members, Latino parents of children with ASD). Family navigation, which has shown promise for ethnically diverse families of children with ASD,[33] or a Spanish-language ASD-specific helpline may assist L-LEP families better access services. Although use of the Internet is lower in families with limited English proficiency,[34] high-quality, low-reading-level Spanish-language Web resources may also help L-LEP families. Diagnostic and therapy providers, particularly those in areas with large Latino populations, should employ bilingual, bicultural staff to better engender trust and assist with connections to ASD services. Finally, education of pediatric providers and community workers in identifying early signs of ASD, how to communicate about ASD in culturally competent ways, and how to most effectively connect families with services might improve care for Latinos.

The study had limitations. Barriers other than those studied may be important in ASD service use. Responses were ascertained by retrospective parent report. Recall bias may affect reporting, although it may not differ by ethnicity/language. We minimized recall bias by surveying families of children diagnosed during the prior 5 years. The study assessed experiences of families whose children ultimately obtained an ASD diagnosis and who were diagnosed at academic medical centers. Consequently, the findings may underestimate barriers to care. Finally, most Latino participants were of Mexican origin. Previous research suggests that Latino health outcomes vary by national origin[35]; however, we lacked adequate numbers of subjects of other origins to conduct subanalyses.

CONCLUSIONS

To our knowledge, this is the largest and only multisite study assessing Latino/white disparities in diagnosis and treatment among children with confirmed ASD. Results suggest that health care quality among Latino families of children with ASD remains problematic. The study brings better understanding of specific problems in the diagnosis and treatment process, which may ultimately improve health care quality and promote health equity among children with ASD.

ABBREVIATIONS

ASD: autism spectrum disorder
L-EP: Latino English proficiency/proficient
L-LEP: Latino limited English proficiency/proficient
NLW: non-Latino white

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