The role of healthcare access, healthcare utilization, and language barriers in the low prevalence of neurodevelopmental disabilities among U.S. Latino children

Abstract

Latino/Hispanic children have substantially lower prevalence of neurodevelopmental disabilities (NDD) than other groups. The reasons for this appear to be complex, but are generally thought to be related to language barriers and lack of access to and utilization of healthcare services. Some researchers have examined these factors in Latino children with NDD, but none has examined whether these factors explain low prevalence of NDD in this population. This research uses nationally representative IPUMS-NHIS data to compare NDD prevalence in whites and Latinos and examines whether healthcare access and utilization as well as language barriers explain this disability disparity. The results show that healthcare access, healthcare utilization, and language barriers do not explain lower rates of NDD among Hispanic/Latino children. Cultural factors may be the reason for low NDD prevalence among Latino children in the United States.

Introduction

Research shows that prevalence of neurodevelopmental disabilities (NDD) among children has increased over time (Blumberg et al., 2013; Boyle et al., 2011; Fombonne, 2009; Getahun et al., 2013). Neurodevelopmental disabilities are a group of conditions that manifest in the developmental period. NDD are characterized by developmental differences that affect social functioning and produce delays in achieving socially expected milestones. NDD include intellectual disabilities which affect mental abilities (such as Down syndrome), communication disorders which affects language and speech, autism spectrum disorder which affects social communication and interaction, attention-deficit hyperactivity disorder which affects attention and impulsivity, neurodevelopmental motor disorders which affect motor functioning (such as Tourette's syndrome), and learning disability which affects perception and processing of information (Psychiatry, 2014). The increase in NDD prevalence is thought to be due to expansion of diagnostic criteria, development of services, and improved awareness (Fombonne, 2009).

Prevalence of NDD varies by race, ethnicity, sex, and geographic location (Blumberg et al., 2013; Getahun et al., 2013). Latino/Hispanic (both terms used interchangeable throughout paper to include both preferences) children, in particular, have not experienced the same increase in NDD diagnosis as white children in the U.S. The low prevalence of NDD among Hispanic children is thought to be due to language barriers, lack of access to health services, and health insurance coverage rather than indicative of a true difference in prevalence (Boyle et al., 2011), but these theories have gone largely untested. We aim to examine whether these factors differentially predict NDD by ethnicity using a large nationally representative dataset over time.

Background

Despite the growth in awareness and prevalence of NDD in the U.S., diagnosis remains low among Hispanic/Latino children (Autism & Investigators, 2012; Boyle et al., 2011; Froehlich et al., 2007). This is important because Latinos are the largest and fastest growing minority population in the United States (Fry, 2008), and also because the reasons for this ethnic disparity in diagnosis rates are thought to be related to inequality and violate the fundamental right to health (Adhanom-Ghebreyesus, 2017). The low prevalence of NDD among Hispanic children is thought to be due to language barriers, lack of access to health services, and health insurance coverage rather than indicative of a true difference in prevalence (Boyle et al., 2011). Hispanics are less likely to have access to and utilize healthcare than other populations (Flores, Olson, & Tomany-Korman, 2005; Raphael, Guadagnolo, Beal, & Giardino, 2009). Hispanic children are more likely to be uninsured and are less likely to have continuous healthcare coverage (Flores et al., 2005). Providers are also less likely to refer Hispanic children to specialists for further care (Flores et al., 2005). Given that Hispanic families are less likely to have access to and utilization of high quality healthcare, it seems likely that children with NDD may be less likely to receive a diagnosis.

Ethnic disparities in healthcare access, use, and quality are also common among children with special healthcare needs (Flores, 2010; Magaña, Parish, Rose, Timberlake, & Swaine, 2012), but there is a dearth of research that specifically examines whether this trend explains the low prevalence of neurodevelopmental disorders among Hispanic children. One study found that access to care is limited among ethnic minorities with autism spectrum disorders (Thomas, Ellis, McLaurin, Daniels, & Morrissey, 2007). Others found that Latino children with autism received lower quality healthcare as compared to white children with autism and Latino children with other developmental disabilities (Magaña et al., 2012; Parish, Magana, Rose, Timberlake, & Swaine, 2012). Specifically, Latino parents were more likely to report that their doctor did not spend enough time with their child, that providers were not sensitive to their values and customs, that doctors did not include them in decision-making about the child's health, and that doctors did not provide enough information. I extend this research by examining whether differences in healthcare access and use is associated with NDD by ethnicity rather than examining healthcare access and use exclusively among children with NDD. In other words, I aim to understand whether ethnic differences in healthcare access and use explain the ethnic NDD diagnosis disparity.

Low healthcare access and utilization among Hispanics may be partially related to language barriers, and language barriers are associated with lower quality of care (Timmins, 2002). Coker (1995) found that Latino children and children in non-English speaking primary households had the lowest rates of time spent with a healthcare provider and provider sensitivity to the family's values and customers. These results remained after adjustment for child health conditions, socioeconomic factors, and health insurance status and access. Kogan et al. (2009) found only slightly lower rates of autism spectrum disorders among Hispanic children as compared to non-Hispanic white children, but the rates were significantly lower among Hispanic children living in households that speak primarily Spanish as compared to households that speak primarily English. This suggests that language barriers may explain the ethnic NDD diagnosis disparity. Other research found that only 29% of primary care pediatricians offered autism screening in Spanish as recommended by the American Academy of Pediatrics guidelines (Zuckerman et al., 2013). Language barriers can affect diagnosis through miscommunication or understanding about symptoms. In one study, primary care pediatricians with higher Spanish proficiency, a Latino provider in their practice, or greater than 25% Latino patients reported less difficulty identifying symptoms of autism in Latino patients than providers with less Spanish proficient, no Latino providers in the practice, or those treating a low percentage of Latino patients (Zuckerman et al., 2013). Language barriers can also affect diagnosis as a result of insensitivity of the provider to Latino culture. Latino families may be less likely to utilize healthcare or feel empowered to discuss their child's health (Parish et al., 2012; Zuckerman, Sinche, Mejia, et al., 2014). Language barriers may contribute to lower quality of care because of misdiagnosis or a lack of understanding of patient symptoms and concerns, but also because providers may not respect or understand cultural differences beyond the language barrier.

Cultural beliefs and practices may also affect health service-seeking behavior. Hispanic families may receive strong support from extended family and avoid professional services as a result of "familismo," or strong familial cohesion and support. If family values conflict with the standards of the majority culture, Hispanic families may view raising a child as their personal responsibility and not as the responsibility of the state or health professionals (Bailey Jr, Skinner, Rodriguez, Gut, & Correa, 1999; Blacher, Lopez, Shapiro, & Fusco, 1997). Further, there is some evidence to suggest that Latino families are less likely to be familiar with NDD, and this may be explained by cultural differences in health literacy or understanding of what constitutes typical behaviors. In other words, Latinos may be less familiar with NDD because they are less likely to medicalize their child's behavioral differences (Zuckerman, Sinche, Cobian, et al., 2014; Zuckerman, Sinche, Mejia, et al., 2014). In this paper, we focus on how economic factors (such as health insurance and access to services) and language barriers predict NDD prevalence among Hispanic children. It is more feasible to measure economic factors and spoken language than it is to measure cultural factors, but we do not rule out the possibility that our results may be influenced by unmeasured cultural influences.

Cultural differences in healthcare practices may be also an important factor in the low prevalence of NDD diagnosis among Hispanic children. NDD is influenced by genetic risk factors, but no biological markers or tests exist to diagnose these disorders. NDD is diagnosed exclusively from observed behavior and parental reporting. The threshold for disordered behavior becomes an arbitrary decision that is likely to be influenced by cultural values and expectations and is derived from white, middle-class, Western cultural standards. Speech and language therapists—often the first provider to determine whether a disability is present—consist primarily of white, middle-class, English-speaking women (Data-USA, 2016; Norbury & Sparks, 2013). Burgeoning research on NDD emerges primarily from Western societies, and this is not representative of the majority of the world's population. The assumption in this research—and in the diagnostic and treatment approaches that are derived from it—is that these "standard" research subjects are representative of the entire population and that findings are universal, but this sample is unusual along many psychological and behavioral dimensions (Henrich, Heine, & Norenzayan, 2010; Norbury & Sparks, 2013). The low prevalence of NDD among Hispanic children may be as a result of different cultural understandings of what constitutes socially acceptable behavior and interaction and as a result of language barriers.

Another factor that may influence prevalence of NDD among Latino families is socioeconomic positioning. Latino families are also more likely to live in poverty than white families (Cauce & Domenech-Rodriguez, 2002), and this in turn may influence access to health insurance and healthcare. Additionally, families who live in poverty may be less concerned about communication differences because other priorities—such as adequate nutrition and housing—are of higher importance (Norbury & Sparks, 2013). Medicaid and higher income have been shown to increase the odds of autism-related service use (such as occupational therapy and behavioral specialist) (Thomas et al., 2007), demonstrating that socioeconomic status affects healthcare service utilization. Because Latino families are more likely to live in poverty, the ethnic NDD disparity may be related to socioeconomic positioning. Other research, however, has shown that socioeconomic positioning did not explain the inverse relationship between percentage of Hispanic students in school districts and the prevalence of autism in Texas school children (Palmer, Walker, Mandell, Bayles, & Miller, 2010).

Rather than a difference in true prevalence of NDD, Hispanic children may not be benefitting from improved awareness of and development of services for NDD. From a medical perspective, the behavioral challenges associated with NDD can negatively impact multiple domains of life such as learning, educational attainment, language, self-care, employment, and capacity for independent living (Johnson, 2016; Lowe et al., 2007). Children who are diagnosed with NDD will be more likely to receive interventions that have been shown to positively impact the domains of life listed above (Petrenko, 2013). Identifying whether the lower prevalence of NDD among Hispanic children is due to the factors identified above can lead to interventions to increase awareness and diagnosis of NDD among Hispanic children, which in turn can lead to higher independence and quality of life in adulthood.

Hispanic children may also experience negative social effects of low rates of NDD diagnosis. From a social perspective, the cultural acceptance and social well-being of Hispanic children may suffer from unrecognized NDD (Norbury & Sparks, 2013). As a result of deviating from socially acceptable behavior and interaction, Hispanic children with unrecognized NDD may experience social exclusion as well as ethnic and cultural discrimination. Socially unacceptable behavior and interactions among Hispanic children with unrecognized NDD can lead to negative social effects for individual children as well as collective ethnic stereotyping.

Hypothesis

The low diagnosis rates of NDD among Latino children are believed to be as a result of a multitude of factors. Cultural differences, inequality in healthcare access and utilization, language barriers, and socioeconomic differences are believed to be the primary reasons for low prevalence of NDD in the Latino community. Much of the research examining healthcare and language focus on children who have previously been diagnosed with NDD, and much of this research finds that low diagnosis rates exist independent of socioeconomic factors. I extend prior research by examining whether language barriers, healthcare access and healthcare utilization may explain the low prevalence of NDD in the Latino population in the United States independent of socioeconomic factors. I compare whites to Latinos in NDD prevalence and examine whether healthcare access, healthcare utilization, and spoken language contribute to prevalence of NDD. While other populations have lower prevalence of NDD than whites, Latino children have significantly lower rates than whites and lower rates than other populations (Zablotsky, Black, & Blumberg, 2017). For this reason, whites are the reference category in this research.

Methods

Data

I use the Integrated Public Use Microdata Series – National Health Interview Survey (IPUMS-NHIS) data for this project, which is a harmonized version of the National Health Interview Survey (NHIS). IPUMS-NHIS is a nationally representative cross-sectional survey collecting information on the health, healthcare access, and health behaviors of the civilian, non-institutionalized United States population (Blewett, Rivera Drew, Griffin, King, & Williams, 2018). Important for this project, the IHIS includes an oversample of Hispanic households. The data are available from 1963-2016, but data on neurodevelopmental disabilities for sample children under age 18 are available from 1997-2006 and for 2008-2017.

Measures

The outcome of interest is NDD among Hispanic and white children. Parents were asked if a doctor or other healthcare provider ever told them that their child has any of the following developmental disabilities: Attention-deficit/hyperactivity disorder, autism, learning disability, other developmental delay, or mental retardation. I combine all disabilities into a dichotomous indicator of any NDD, and in the future will analyze each NDD separately.

For health insurance, respondents were asked if they have any health insurance and if they have any public insurance (including Medicaid, CHIP, or another state or local health insurance plan coverage). For healthcare access, respondents were asked if they needed medical care in the past 12 months but did not receive it because it was too expensive. For healthcare utilization, respondents were asked if they have a usual provider that they see when they need medical care.

I also considered other demographic predictors that may be affect the ethnicity NDD disparity. I included a measure indicating whether the interviewed was conducted in English or Spanish to indicate whether what language the respondent speaks. While there are more specific variables regarding language (for example what language is spoken at home or what language the respondents usually speaks), these measures are only available for a subset of the sample years. In the future, I will incorporate these measures into a secondary analysis for robustness checks. Finally, I include a measure indicating how long the respondent have lived in the United States. I recoded this variable to include all those who were born in the United States as the reference group. Respondents were asked about a variety of demographic characteristics for themselves and their child including gender, number of children in the household, household income which was translated to an income-to-poverty ratio by IPUMS-NHIS research staff, and age.

Results

Table 2 reports the initial results for a logistic regression analysis of any NDD diagnosis on various predictors of interest. Hispanic children have 37% lower odds of have any NDD diagnosis, and the results are statistically significant. Those without health insurance, who do not have a usual healthcare provider, who have lived in the U.S. less than five years, and whose interview was conducted in Spanish are less likely to have children with an NDD diagnosis. Children whose parents have public health insurance coverage and who needed medical care but did not receive it due to cost are significantly more likely to have a diagnosis of any NDD.

The odds of diagnosis among Hispanic children do not increase substantially when each of the predictors of interest are added to the model. These results indicate that health insurance access and utilization, language barriers, and years in the United States do not explain low diagnosis rates of NDD among the Hispanic/Latino population. Figure 2 depicts the interaction effects for each predictor. For health insurance, white children with NDD have substantially higher rates of health insurance than Hispanic children with NDD. While about 5% of white children with NDD do not have health insurance coverage, nearly 80% of white children with NDD do have health insurance coverage. For Hispanic children, about 15% with health insurance have an NDD diagnosis while about 2% without health insurance do. These differences in NDD demonstrate that health insurance is an important characteristic for NDD among white children, but less so for Hispanic children. Regarding public health insurance, rates of NDD are higher among white children who do not have public insurance. This is likely related to the fact that white children are more likely to have private health insurance rather than public health insurance, and something that I will explore in further detail prior to the PAA annual conference. One interesting finding is that Hispanic children with public insurance are more likely to have an NDD diagnosis than Hispanic children without public health insurance coverage. These results suggest that social safety nets may increase NDD rates among the

Hispanic population, and that the lower rates of NDD among Hispanics is not as a result of a true difference in prevalence.

One surprising finding was related to NDD rates among those who have a typical medical provider. White children who do not see a typical medical provider have higher rates of NDD than white children who have a usual medical provider. The trend is similar for Hispanic children, but rates of NDD are lower among Hispanic children regardless of whether they have a usual medical provider. I will examine this result further prior to the PAA annual meeting to try to understand this surprising result.

White children who did not receive medical care due to cost have higher rates of NDD than Hispanic children who did not receive medical care due to cost, and rates are similar among both whites and Hispanics who did not avoid medical care due to cost. Whites who did not receive care due to cost have substantially higher NDD rates than Hispanics who did not receive care due to cost. This suggests that whites receive healthcare despite cost limitations more than Hispanics, and that this is manifesting in higher rates of NDD diagnosis among white children. Finally, Hispanics who were interviewed in English have much lower rates of NDD than whites who were interviewed in English, but Hispanics who were interviewed in Spanish do not have higher rates of NDD than Hispanics who were interviewed in English. NDD rates are similar among Hispanics who were interviewed in English and Spanish. These results suggest that access to language services does not significantly increase the odds of NDD diagnoses.

Discussion

These results suggest that healthcare access, healthcare utilization, and language barriers do not explain lower rates of NDD among Hispanic/Latino children in the United States. Prior to the PAA annual conference, I plan to examine and add the following:

- Other potential covariates (particularly related to socioeconomic position and citizenship) that may be associated with both the predictor of interest and the outcome of interest and include them in the models
- Generate and include descriptive tables
- Examine the predictors of interest using separate NDDs as the outcome as compared to using *any* NDD as the outcome of interest
- Write a full discussion section considering the implications of these findings that will include promotion of research examining how cultural beliefs and factors relate to low NDD among Hispanic/Latino children since as we have ruled out healthcare access, utilization, and language barriers
- Include motivation, figure, and discussion for the relationship between years in the US and any NDD diagnosis since this result produced interesting findings in the model (odds of NDD decline the longer the parent has been living in the U.S.)
- Consider and include other tests of robustness to ensure reliability of the findings

Limitations

It is possible that the results are related to sample or the manner in which the data were collected. Parents may not report that children have NDD. Children may have received a diagnosis at one point in time but lack of precision in diagnosis at very young ages could mean some children met the diagnostic criteria for NDD at one time point but not at the time of survey. We perceive this to be a minimal limitation as the parents were asked if their child was ever told by a healthcare provider that they child had a NDD, but it is possible that parents would not report a prior diagnosis if the child no longer has the diagnosis.

Racial minorities and children from low socioeconomic status households are also diagnosed at later ages, so it is possible that the IHIS does not capture diagnoses among certain groups (Mandell et al., 2009). To minimize this limitation, we controlled for the age of the children in the sample.

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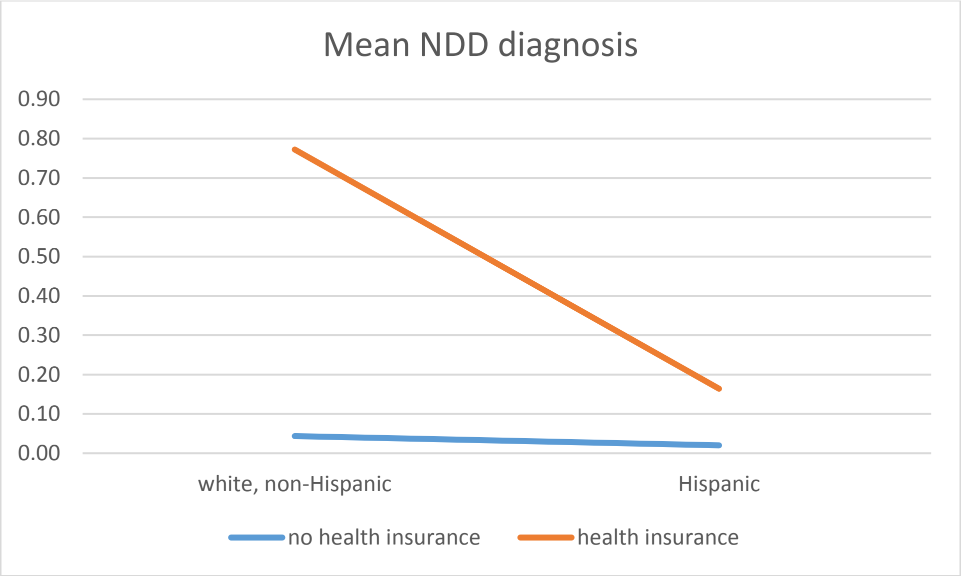
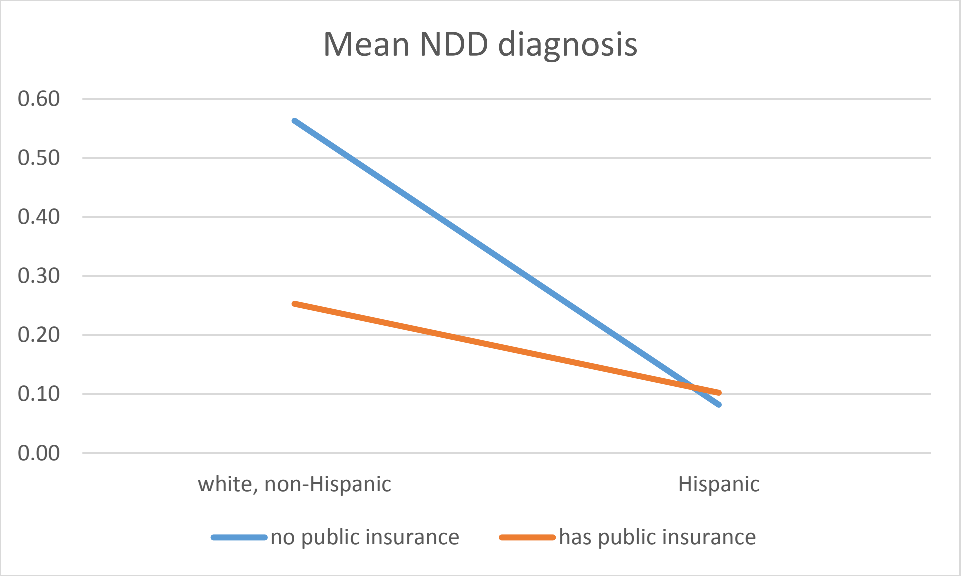
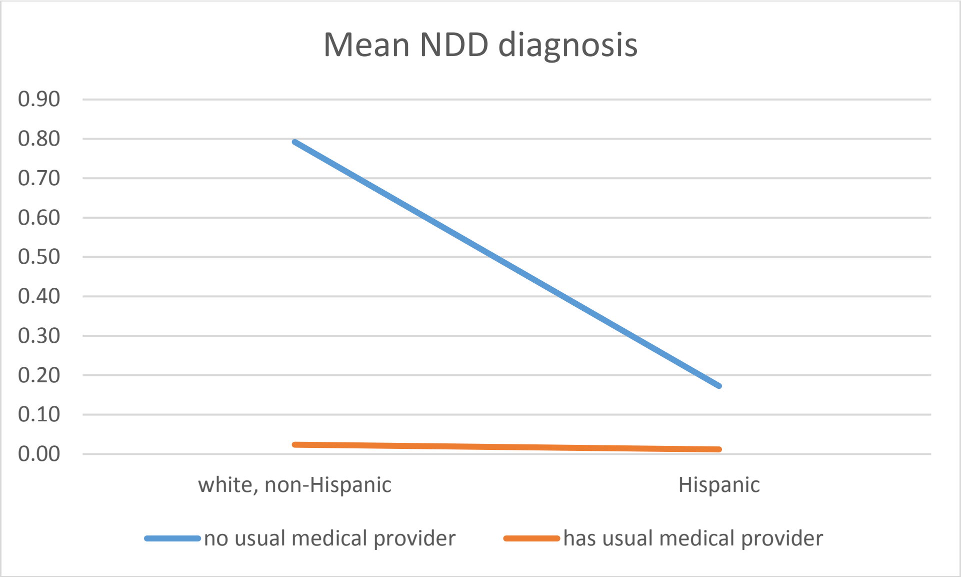
Table 2. Logistic regression results

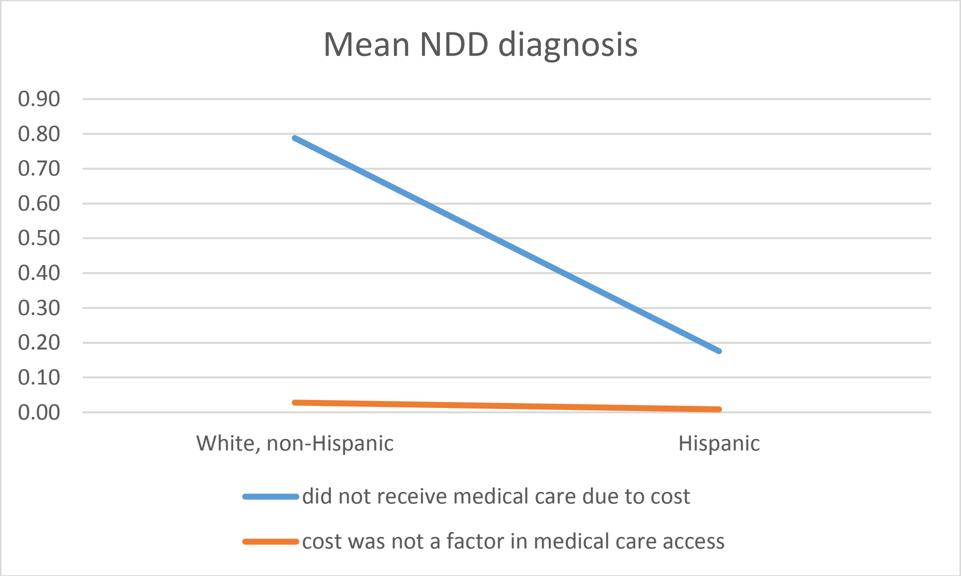
	Model 1			Model 2			Model 3			Model 4		
Any Neurodevelopmental Disability (ADHD, autism, learning disability, developmental delay, mental retardation)	*OR*	*(Std. Err.)*		*OR*	*(Std. Err.)*		*OR*	*(Std. Err.)*		*OR*	*(Std. Err.)*	
Health insurance												
Respondent is Hispanic or Latino (ref. is white, non-Hispanic)	0.63	(0.01)	***	0.63	(0.01)	***	0.95	(0.04)	***	0.58	(0.01)	***
No health insurance				0.86	(0.03)	***	0.65	(0.01)		0.76	(0.04)	***
Interaction: no health insurance * Hispanic/Latino							0.75	(0.06)	***	0.72	(0.05)	***
Intercept	0.16	(0.00)	***	0.16	(0.00)	***	0.16	(0.00)	***	0.16	(0.00)	***
Has any form of public health insurance (Medicaid, CHIP, or other state or local insurance)												
Respondent is Hispanic or Latino (ref. is white, non-Hispanic)	0.63	(0.01)		0.52	(0.01)	***	0.62	(0.02)	***	0.60	(0.02)	***
Has public insurance				1.85	(0.04)	***	1.98	(0.05)	***	2.22	(0.07)	***
Interaction: has public insurance * Hispanic/Latino							0.72	(0.03)	***	0.74	(0.03)	*
Intercept	0.16	(0.00)	***	0.14	(0.00)	***	0.14	(0.00)	***	0.07	(0.00)	***
Health care access												
Respondent is Hispanic or Latino (ref. is white, non-Hispanic)	0.63	(0.01)	***	0.62	(0.01)	***	0.60	(0.01)	***	0.55	(0.01)	***
Needed medical care in past 12 months but did not receive it due to cost				2.09	0.11	***	2.27	(0.13)	***	1.81	(0.12)	***
Interaction: needed care but could not afford it * Hispanic/Latino							0.80	(0.07)	*	0.79	(0.09)	*
Intercept	0.16	(0.00)	***	0.16	(0.00)	***	0.16	(0.00)	***	0.13	(0.00)	***
Healthcare utilization												
Respondent is Hispanic or Latino (ref. is white, non-Hispanic)	0.63	(0.01)	***	0.63	(0.01)	***	0.64	(0.01)	***	0.56	(0.01)	***
Has usual medical provider				0.87	(0.04)	**	0.92	(0.06)		0.68	(0.04)	***
Interaction: has usual medical provider * Hispanic/Latino							0.83	(0.08)	*	0.79	(0.08)	*
Intercept	0.16	(0.00)	***	0.16	(0.00)	***	0.16	(0.00)	***	0.13	(0.01)	***
Years living in the United States												
Respondent is Hispanic or Latino (ref. is white, non-Hispanic)	0.63	(0.01)	***	0.64	(0.01)	***	0.64	(0.01)	***	0.58	(0.01)	***
Years in U.S. (reference is born in the U.S.)												
<1 year				0.31	(0.11)	**	0.12	(0.12)	*	0.12	(0.13)	*
1 to <5 years				0.52	(0.06)	***	0.37	(0.08)	***	0.37	(0.08)	***
5 to <10 years				0.93	(0.08)		1.28	(0.20)		1.07	(0.18)	
10 to <15 years				1.06	(0.11)		1.37	(0.22)	*	0.91	(0.16)	
15+ years				1.03	(0.19)		1.01	(0.29)		0.52	(0.15)	*
Interaction: years in the U.S. * Hispanic/Latino												
<1 year * Hispanic/Latino							4.08	(4.39)		2.87	(3.18)	
1 to <5 years							1.70	(0.41)	*	1.22	(0.31)	
5 to <10 years							0.57	(0.11)	**	0.42	(0.08)	***
10 to <15 years							0.61	(0.12)	*	0.46	(0.10)	***
15+ years * Hispanic/Latino							1.03	(0.38)		0.82	(0.32)	
Intercept	0.16	(0.00)	***	0.16	(0.00)	***	0.16	(0.00)	***	0.13	(0.01)	***
Language												
Respondent is Hispanic or Latino (ref. is white, non-Hispanic)	0.63	(0.01)	***	0.72	(0.02)	***	--	--	--	0.67	0.02	***
Interview was conducted in Spanish				0.63	(0.02)	***	--	--	--	0.50	0.02	***
Intercept	0.16	(0.00)	***	0.16	(0.00)	***	--	--	--	0.14	0.01	***

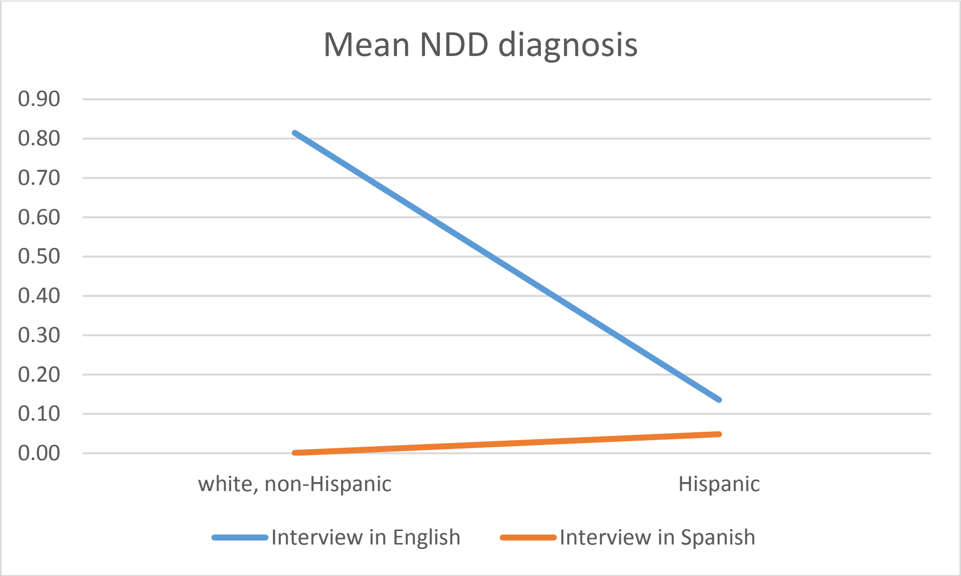
Notes: Sample size is 139,997. Sample is limited to one child under age 18 and one parent who were chosen to be interviewed and have valid responses to all variables included in the models. Results are pooled for years 1997-2006 and 2008-2017, and person weights are used and adjusted so that total sample represents the U.S. population (on average) for the twenty year period. Model 1 includes the bivariate association between ethnicity and any NDD. Model 2 includes a secondary predictor of interest. Model 3 includes an interaction between ethnicity and the secondary predictor of interest. Model 4 includes the following covariates: gender, family size, poverty ratio, and age of the child. Asteriks indicate statistical significance where p<.05=***; p<.01=**, and p<.001=***.


Mean NDD diagnosis
0.90
0.80
0.70
0.60
0.50
0.40
0.30
0.20
0.10
0.00
white, non-Hispanic
Hispanic
no health insurance
health insurance


Mean NDD diagnosis
0.60
0.50
0.40
0.30
0.20
0.10
0.00
white, non-Hispanic
Hispanic
no public insurance
has public insurance


Mean NDD diagnosis
0.90
0.80
0.70
0.60
0.50
0.40
0.30
0.20
0.10
0.00
white, non-Hispanic
Hispanic
no usual medical provider
has usual medical provider


Mean NDD diagnosis
0.90
0.80
0.70
0.60
0.50
0.40
0.30
0.20
0.10
0.00
White, non-Hispanic
Hispanic
did not receive medical care due to cost
cost was not a factor in medical care access


Mean NDD diagnosis
0.90
0.80
0.70
0.60
0.50
0.40
0.30
0.20
0.10
0.00
white, non-Hispanic
Hispanic
Interview in English
Interview in Spanish