International Journal of MCH and AIDS (2015), Volume 3, Issue 2, 159-167

INTERNATIONAL JOURNAL
of MCH and AIDS
ISSN 2161-864X (Online)
ISSN 2161-8674 (Print)

Available online at www.mchandaids.org

ORIGINAL ARTICLE

Disparities in Healthcare Access and Utilization among Children with Autism Spectrum Disorder from Immigrant Non-English Primary Language Households in the United States

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ABSTRACT

Background: The prevalence of autism spectrum disorder (ASD) in United State (US) has surged from 1 in 150 children in 2007 to 1 in 88 children in 2012 with substantial increase in immigrant minority groups including Hispanic and Somali children. Our study objective is to examine the associations between household language among children with ASD and national health quality indicators attainment.

Methods: We conducted bivariate and multivariate logistic regression analyses using cross-sectional data from the publicly-available 2009-2010 National Survey of Children with Special Health Care Needs (NS-CSHCN) to investigate the association between household language use and quality indicators of medical home, adequate insurance, and early and continuous screening.

Results: Approximately, 28% of parents of children with ASD from non-English primary language (NEPL) households reported their child having severe ASD as compared with 13% of parents from English primary language (EPL) households. Older children were more likely to have care that met the early and continuous screening quality indicator, while lower income children and uninsured children were less likely to have met this indicator.

Conclusions and Global Health Implications: Despite the lack of differences in the attainment of quality indicators by household language, the higher severity found in children in NEPL households suggests that they are exceptionally vulnerable. Enhanced early screening and identification for these children and supporting their parents in navigating the complex US health care delivery system would increase their participation in early intervention services. Immigration of children with special health care needs from around the world to the US has been increasing from countries with diverse healthcare systems. Our findings will help to inform policies and interventions to reduce health disparities for children with ASD from immigrant populations. As the prevalence of ASD has increased worldwide, understanding of the condition and care-seeking behavior in migrant populations is especially valuable.

Key words: Autism Spectrum Disorder • Household Language • Insurance • Medical Home

Background

The United States (US) prevalence of autism spectrum disorder (ASD) surged from 1 in 150 children in 2007 to 1 in 88 children in 2012 with substantial increase in immigrant minority groups including Hispanic and Somali children.[1-3] ASD is characterized by atypical development and pervasive impairment in social interaction impairments, verbal and nonverbal communication, and restricted, repetitive, and stereotyped patterns of behavior.[4] Recognizing the increasing global burden of ASD, the United Nations passed a new resolution on access to ASD care in 2012.[5] A systematic review on global prevalence published in the same year reported the median prevalence estimate to be 62/10,000 and the lack of support of differences in prevalence by geographic region or of a strong impact of ethnic/cultural or socioeconomic factors.[6]

Due to the complex nature of ASD, children with ASD and their families often confront many challenges in receiving comprehensive health care and especially experience unmet specialty and therapy care needs.[7,8] The barriers to health care access are further exacerbated for children with ASD from immigrant families with limited English proficiency (LEP).[9] Parental LEP has been associated with risks of adverse outcomes in children's health and disparities in medical and oral health, access to care, and use of services with challenges in understanding clinical evaluation results, prescription instructions, follow-up appointments, referral to specialist and therapy-related documents.[10-12]

Previous research found that children with special health care needs (CSHCN) from non-English primary language (NEPL) households have less access to medical home, usual source of care, family-centered care, and insurance coverage adequacy.[13-15] The US Federal Maternal and Child Health Bureau (MCHB) defined CSHCN as children who have one or more chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally.[16] MCHB is the US federal agency responsible for ensuring the health and well-being of women, infants and children, including CSHCN. Children with ASD are among CSHCNs. Efforts to improve primary care quality through application of the medical home model encourage providers to invest more time in fostering the parent-provider relationship and timely access to care such as providing reliable same-day sick care, expanding after hours coverage, improving patient safety, enhancing care coordination, and providing overall culturally and linguistically appropriate services.[17,18] Our objective is to examine the association between children with ASD from NEPL households and health care access using data from the 2009-2010 National Survey of Children with Special Health Care Needs (NS-CSHCN) to advance understanding of disparities in health care access and utilization.

Methods

Data Source

The publicly-available NS-CSHCN is a national, cross-sectional telephone survey with independent random samples from 50 states and the District of Columbia previously administered in 2000-2001 and 2005-2006 by the National Center for Health Statistics (NCHS) of the US Centers for Disease Control and Prevention (CDC) with funding support from MCHB at the Health Resources and Services Administration (HRSA) in the US Department of Health and Human Services. The 2009-2010 NS-CSHCN interview completion rates were 83.6% for the landline sample, 76.6% for the cell-phone sample, and 80.8% for the combined sample.[19] The survey respondents is comprised of parent or guardian with in-depth knowledge about the child's health status and health care access. The survey sample consisted of 40,242 children.[20] The available survey languages included the following: English, Spanish, Mandarin, Cantonese, Vietnamese and Korean. The NS-CSHCN survey topics include child health, insurance status, access to health care, preventive care, family-centered care, access to community-based services, impact of child's health on family, transition to adulthood, and child and family demographics.[21]

Variables

The major independent variable was primary household language dichotomized as whether households spoke English as the primary language at home (EPL) or household did not speak English as the primary language at home (NEPL). The outcome variables of interest are the following three quality indicators identified by MCHB in collaboration with its partners: 1) medical home, 2) insurance adequacy, and 3) early and continuous screening. First, the medical home indicator is comprised of five subcomponents: 1) access to usual source of sick and well care; 2) have a personal doctor or nurse; 3) getting needed referral for health care services; 4) effective care coordination; and 5) family-centered care.[22] Second, insurance adequacy indicator is operationalized by five subcomponents: 1) has current health insurance benefits that meet his/her needs; 2) had no gaps in coverage in the past year; 3) had insurance that usually or always covered needed services; 4) had reasonable uncovered costs; and 5) has health insurance that enables him/her to see needed providers. Finally, early and continuous screening indicator contained two subcomponents of receipt of routine preventive medical care and preventive dental care during the past year.

Children with ASD were defined as children whose parent or guardian responded positively to the following question: "Has a doctor or other health care provider ever told you that [subject child] had autism, Asperger's disorder, pervasive developmental disorder, or other autism spectrum disorder?" Sociodemographic covariates included in the multivariate model are as follows: child's age (2-5, 6-11, 12-17 years), race/ethnicity (non-Hispanic white, non-Hispanic black, Hispanic, and other), household poverty status measured as a ratio of the family income to the federal poverty level (FPL) in four categories (<100%, 100-199%, 200-399%, ≥400%) parental education level (less than high school [<12 years]; high school graduate [12 years]; and more than high school [>12 years]; and type of health insurance (private, public, both public and private, and uninsured).

Statistical Analysis

Analysis was performed using SAS version 9.3.[23] Bivariate analyses examined the differences between EPL and NEPL households of children with ASD with respect to sociodemographic factors, MCHB's three quality indicators and their subcomponents. Quality indicators were further analyzed for association with household language use in the multivariate logistic regression model while controlling for children's age, race/ethnicity, household poverty level, parental education level, and insurance type. Adjusted odds ratios (aOR) and 95% confidence intervals (CI) were computed by using the beta coefficients and standard errors. The Taylor series (linearization) method was used to estimate the covariance matrix of the regression coefficients to account for complex sample design involving stratification, clustering, and multistage sampling of the NS-CSHCN.[24] The study was approved by the institutional review board of the University of Maryland, College Park, Maryland, USA.

Results

The final analytic sample included 138 children with ASD from NEPL households and 3,840 children from EPL households. Table 1 summarizes the sample sociodemographic characteristics. Children from EPL households were predominantly non-Hispanic White (64%) while those from NEPL households were primarily Hispanic (78%). 52% of children from NEPL households were poor (below 100% FPL) compared to only 22% of children from EPL households. For children aged 2-5 years, the proportion of children with ASD from NEPL households (43%) exceeded EPL households (16%). About 28% of parents of children with ASD from NEPL households reported their child having severe ASD, as compared with 13% of parents from EPL households. About 44% of children from EPL households had private insurance as compared with 20% in NEPL households. There were no significant differences in gender and family structure.

Table 2 contains results of the bivariate analysis of the three quality indicators and their respective subcomponents. Among the subcomponents of medical home quality indicator, only "encounter problems getting needed referrals" yielded a significant chi-square p-value at <0.01 where 11% EPL households reported difficulties as compared with 2% of NEPL households. There were no significant differences between EPL and NEPL households

Table 1. Socioeconomic and Demographic Characteristics of Children with Autism Spectrum Disorders (ASD), Aged 2-17 Years in English Primary Language and Non-English Primary Language Households in United States

Characteristics (weighted percents)	EPL Households		NEPL Households		Chi-square p-value
	N=3840		N=138		
	%	SE	%	SE	
Child race/ethnicity					<0.01
Non-Hispanic White	64.2	1.47	2.9	1.18	
Non-Hispanic Black	13.2	1.04	0.7	0.74	
Hispanic	12.6	1.00	78.3	6.92	
Non-Hispanic Multirace/other	10.0	1.13	18.1	6.90	
Gender					
Male	78.0	1.19	72.3	8.51	0.48
Female	22.0	1.19	27.7	8.51	
Child's age					<0.01
2-5 years	16.4	1.06	43.4	8.08	
6-11 years	47.0	1.44	32.2	7.36	
12-17 years	36.6	1.33	24.4	5.86	
Household poverty status (ratio of family income to poverty threshold)					
<100%	21.5	1.23	51.6	7.89	<0.01
100-199%	22.7	1.17	15.3	3.85	
200-399%	30.0	1.36	20.1	5.41	
400+%	25.8	1.16	12.9	6.87	
Parental education					<0.01
Less than high school	8.9	1.03	34.6	8.32	
High school graduate	16.9	1.08	24.2	5.89	
More than high school	74.2	1.34	41.2	7.61	
Household structure					0.45
2-parent	66.4	1.47	73.4	8.44	
Mother only	24.3	1.40	13.9	4.23	
Other	9.3	0.92	12.7	8.70	
Insurance Type					<0.01
Private only	43.8	1.38	20.4	4.72	
Public only	35.8	1.45	41.4	7.21	
Both public and private	14.9	1.04	30.2	9.30	
Uninsured	5.6	0.61	8.1	4.10	
Severity of ASD					0.04
Mild	49.5	1.66	47.4	8.34	
Moderate	37.2	1.58	24.3	6.45	
Severe	13.3	1.21	28.3	9.82	

Source: The 2009-2010 National Survey of Children with Special Health Care Needs. EPL = English as the primary language; NEPL = Non-English primary language

with respect to the quality indicators of adequate insurance and early and continuous screening and their subcomponents.

In Table 3, the adjusted odds ratios (aORs) of three quality indicators were estimated from the multivariable logistic regression analysis while

Table 2. Observed (Weighted) Prevalence of Medical Home, Adequate Insurance, and Early and Continuous Screening Quality Indicators among Children with Autism Spectrum Disorders (ASD)

	EPL household		**NEPL household**		**Chi-square p-value**
	N=3840		**N=138**		
	%	**SE**	**%**	**SE**	
Medical home quality indicator					
Met medical home criteria	24.0	1.11	16.6	4.80	0.31
1. Do not have usual sources for sick and well care	11.3	0.99	10.9	3.34	0.91
2. Do not have personal doctor or nurse	6.6	0.67	2.4	1.59	0.11
3. Encounter problems getting needed referrals	11.2	0.85	2.1	0.75	<0.01
4. Do not meet 1 or more needed elements of care coordination	59.1	1.38	54.5	6.49	0.67
Providers do not spend enough time	30.8	1.33	30.8	6.27	0.34
Providers do not listened carefully	20.4	1.39	17.7	4.24	0.21
Providers are not sensitive to family values and customs	16.6	1.13	25.6	7.15	0.09
Providers do not provide the needed information	30.9	1.41	28.5	6.00	0.30
Providers do not help you feel like a partner in child's health care	21.8	1.37	15.5	4.73	0.14
5. Does not have family-centered care	49.6	1.43	50.9	8.01	0.41
Families need help in coordinating health care but did not receive	32.5	1.44	23.2	4.75	0.28
Family dissatisfied with health care provider communication with other clinicians	47.5	1.44	42.3	6.58	0.68
Family dissatisfied with provider communication with child care, education and vocational programs	32.2	1.34	32.1	6.00	0.67
Adequate insurance quality indicator					
Met adequate insurance criteria	49.7	1.42	48.5	7.98	0.82
Has insurance	97.5	0.35	96.0	1.93	0.33
No gaps in insurance	92.0	0.75	91.2	2.93	0.07
Health insurance benefits meet child needs	73.0	1.26	73.7	7.13	0.92
Non-covered insurance charges reasonable	59.8	1.38	64.9	6.58	0.46
Insurance allows child to see needed providers	76.9	1.15	82.5	4.30	0.25
Early and continuous screening quality indicator					
Met early and continuous screening criteria	78.8	1.16	74.9	5.79	0.49
Receipt of routine preventive medical care	90.2	0.80	91.2	2.92	0.76
Receipt of preventive dental care	85.9	1.01	80.6	5.26	0.27

Source: The 2009-2010 National Survey of Children with Special Health Care Needs. EPL = English as the primary language; NEPL = Non-English primary language

controlling for significant sociodemographic variables of children's age, race/ethnicity, household poverty level, parental education level, and insurance type. Children with ASD from NEPL households did not differ from those from EPL households for the three indicators examined. Children whose parents had graduated from high school were more likely to have experienced care meeting the adequate insurance quality indicator than those with parents with at least some college education (aOR=1.50, 95% CI=1.10, 2.05). Children aged 6-11 (aOR=1.86, 95% CI=1.28, 2.69) and 12 -17 (aOR=1.50, 95% CI=1.04, 2.18) were more likely to have care that met the early and continuous screening quality indicator. Children from households with less income as well as those who were uninsured were less likely to have met the same indicator.

conclusion

A recent study found that some children diagnosed with ASD have lost their diagnosis in later childhood

Table 3. Adjusted Odds Ratios for Care Meeting Quality Indicators among Children with Autism Spectrum Disorders (ASD)

	Care met medical home quality indicator			Care met adequate insurance quality indicator			Care met early & continuous screening quality indicator		
	OR	95% CI		OR	95% CI		OR	95% CI	
Primary household language									
Non-English	0.79	0.38	1.63	0.94	0.47	1.88	0.91	0.43	1.90
English	1.00	ref		1.00	ref		1.00	ref	
Child's age									
2 to 5	1.00	ref		1.00	ref		1.00	ref	
6 to 11	0.98	0.68	1.40	0.95	0.69	1.31	1.86	1.28	2.69
12 to 17	1.17	0.81	1.70	1.19	0.86	1.65	1.50	1.04	2.18
Race/ethnicity									
Non-Hispanic White	1.00	ref		1.00	ref		1.00	ref	
Non-Hispanic Black	0.94	0.62	1.43	1.04	0.72	1.50	1.08	0.66	1.74
Hispanic	0.89	0.60	1.33	0.81	0.56	1.17	1.43	0.84	2.42
Other	0.74	0.48	1.16	1.44	0.88	2.33	0.87	0.54	1.40
Household poverty status (ratio of family income to poverty threshold)									
Below 100%	1.05	0.68	1.62	1.26	0.88	1.80	0.53	0.31	0.91
100-199%	1.14	0.80	1.61	1.14	0.83	1.55	0.50	0.32	0.79
200-399%	0.97	0.72	1.32	0.93	0.69	1.26	0.64	0.43	0.94
At or above 400%	1.00	ref		1.00	ref		1.00	ref	
Parental education									
Less than high school	0.65	0.37	1.12	1.20	0.72	1.26	0.60	0.34	1.07
High school grad	1.33	0.95	1.87	1.50	1.10	2.05	1.03	0.71	1.51
More than high school	1.00	ref		1.00	ref		1.00	ref	
Insurance type									
Private only	1.00	ref					1.00	ref	
Public only	0.75	0.54	1.05				1.16	0.79	1.71
Both public and private	0.85	0.58	1.25				1.33	0.80	2.19
Uninsured	0.64	0.36	1.12				0.39	0.23	0.65

Source: The 2009-2010 National Survey of Children with Special Health Care Needs. OR = Odds ratio; SE = Standard error; CI = Confidence interval; ref = Reference

through potential development of compensatory skills for autism-related deficits upon early identification.[25] Entry into early intervention program for children ages 0-3 years old is critical to maximize health outcomes and to improve cognitive performance, language skills, and adaptive behavior skills for young children with ASD.[26] In our study, more parents of children with ASD from NEPL households reported severe ASD diagnosis, while child's older age was positively associated with receiving care meeting early and continuous screening indicators. The severity reported may have resulted from delays in accessing services that could lead to diminished treatment outcomes.[27] If clinical providers and early intervention specialists can enhance early screening and identification for children with ASD from NEPL households, then children may benefit from early intervention services and be less susceptible to the long-term negative consequences and have greater potential for optimal health development throughout the life course.[28]

Despite the lack of differences in quality indicator attainments by household language after adjusting for race/ethnicity, income, education and insurance, NEPL children with ASD remain exceptionally vulnerable. Supporting parents from NEPL households with navigation through the often unfamiliar and complex US health care delivery system will be instrumental in the successful development of their children with ASD.[29] Public health systems could develop or enhance public awareness programs that target outreach to NEPL households to improve their health literacy on ASD issues and to inform them on availability of specialty or therapy services. In addition, family support organization at the state and local level can increase outreach and assist in the empowerment of NEPL households to advocate for services requiring referral. Furthermore, public health systems could collaborate with professional organizations to support the provision of comprehensive, culturally competent training for clinicians, allied health professionals, and public health professionals. Enhanced clinical provider training will improve their capacity to engage in direct service delivery when working with NEPL households.

This study has some limitations. Firstly, the 2009-2010 NS-CSHCN is a cross-sectional survey conducted in English, Spanish, and four Asian languages, with the screener being in English or Spanish. This may bias the non-English respondents towards those who are more educated and fluent in English, resulting in a likely underestimate of risk for the actual immigrant populations in the U.S. Secondly, the cross-sectional nature of the survey data collections does not allow for causal inferences. Thirdly, although the survey does not collect information on citizenship status, households with undocumented residents who may be at the highest risk for adverse health outcomes are less likely to participate in the survey due to fear of exposing their immigration status. This selection bias may potentially exclude the most underserved populations. Finally, in addition to having a language barrier, household language is a proxy for immigrant household status and the length of stay of the family in the United States. NEPL households are the least acculturated ones and a subset of households that have at least one immigrant parent. While Asian ethnicity was not disclosed in this public-use dataset, we can infer that NEPL "others" are primarily Asians.

Global Health Implications

Immigration of children from around the world to the United States has been dramatically increasing from countries with diverse healthcare systems and children with various special health care needs. As the US Limited English Proficiency population has grown to 9% in 2011, many more families affected with ASD will require special assistance.[30] Our study findings will help to inform programmatic policies and interventions to reduce health disparities for children with ASD from immigrant populations both in the US and abroad. As the prevalence of ASD has been increasing worldwide, a greater understanding of the health status and care seeking behavior in migrant populations, even in non-US developed countries of the world, is especially valuable.[5]

Conflicts of Interest: *The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.* **Financial Disclosure:** *None to report.* **Funding/Support:** *The authors received no financial support for the research, and/or authorship of this article.* **Ethical Approval:** This study was certified exempt by the Institutional Review Board of the University of Maryland, College Park.

Key Messages

- Health disparities exist in the timely receipt of early and continuous for children ASD from NEPL household.
- From a policy perspective, supporting the availability of early and continuous screening to identify required services and supports for children with ASD from NEPL households and their families holds the greatest promise for their optimal health development throughout the life course.
- With the prevalence of autism spectrum disorder (ASD) rising in US and aboard, the global burden of ASD will likely increase.

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