

Autism Spectrum Disorders and Developmental Disabilities in Children From Immigrant Families in the United States

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KEY WORDS

autism spectrum disorder, immigrant, family

ABBREVIATIONS

ADD—attention deficit disorder

ADHD—attention-deficit/hyperactivity disorder

ASD—autism spectrum disorder

CI—confidence interval

CSHCN—children with special health care needs

DD—developmental disability

NSCH—National Survey of Children's Health

OR—odds ratio

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abstract

OBJECTIVES: Recent census data show that nearly one-quarter of US children have at least 1 immigrant parent; moreover, there has been a dramatic increase in children diagnosed with autism spectrum disorders (ASDs) and select developmental disabilities (DDs). However, little is known about access to medical home and adequacy of insurance coverage for children with ASDs and select DDs from immigrant families.

METHODS: By using the 2007 National Survey of Children's Health, we compared children with ASDs and select DDs from immigrant ($n = 413$, foreign born or reside with at least 1 immigrant parent) and nonimmigrant ($n = 5411$) families on various measures of medical home and insurance coverage. We used weighted logistic regression to examine the association between immigrant family and selected outcome measures while controlling for confounding factors.

RESULTS: Compared with nonimmigrant families, children with ASD and select DD from immigrant families were more than twice as likely to lack usual source of care and report physicians not spending enough time with family. Furthermore, multivariable analyses indicate that insurance coverage is an important factor in mitigating health care barriers for immigrant families.

CONCLUSIONS: The study demonstrates important areas of deficits in the health care experiences of children with ASD and select DD from immigrant households. Public policy implications include increasing access to existing insurance programs, augmenting public awareness resources for ASD and select DD, and offering assistance to immigrant families that are struggling with the medical needs of their children. *Pediatrics* 2012;130:S191–S197

In 2009, 23% of children in the United States were foreign born or resided with at least 1 immigrant parent.¹ Children <6 years had the highest proportion of immigrant parents.² Many children of immigrant families live in low-income households, have parents with low educational levels, and use fewer public benefits.^{3,4} For immigrant families with children with special health care needs (CSHCNs), including children with autism spectrum disorders (ASDs) and other developmental disabilities (DDs), these factors contribute to barriers in access to services and social challenges, such as limited awareness regarding resources, decreased likelihood of accessing mental health and social services,^{5,6} and fewer opportunities for family-to-professional collaboration.^{7,8}

ASDs are a group of developmental disabilities characterized by atypical development in socialization, communication, and behavior with associated impairments affecting multiple areas of a person's life.⁹ Prevalence data from the Health Resources and Services Administration and the Centers for Disease Control and Prevention both indicated, on average, ~1% or 1 child in every 110 was classified as having an ASD.^{10,11} In addition, there has been a 17% increase in all DDs from 1997 to 2008 that has been caused in large part by shifts in the prevalence of attention-deficit/hyperactivity disorder (ADHD) and ASD. The prevalence of children with learning disabilities was 7.7%.¹² From 1997 to 2005, children with DDs were 2 to 8 times more likely to have more health care visits, receive special education services, undergo a surgical or medical procedure, and visit medical specialists, allied health professionals, and/or emergency departments.¹³ To address this growing public health concern, Congress enacted the Combating Autism Act of 2006¹⁴ to address ASDs and other DDs through research, screening, intervention, and education.

Immigrant families with CSHCNs encounter a unique set of socioeconomic, cultural, and linguistic challenges that can further exacerbate access to health care, medical home, insurance, and communication of accurate medical information.^{15,16} Given the growing number of children from immigrant families, the differences in prevalence of ASDs and select DDs across studies,^{17–19} and the complexity of service systems for ASDs and DDs, it is important to understand the patterns of health care experience for families and maximize health outcomes of children with ASDs and select DDs from immigrant families to minimize overall cost for all stakeholders.^{20,21} Select DDs in this study includes children reported having ADHD or attention deficit disorder (ADD), learning disabilities, and any developmental delay, which are highly prevalent DDs.²²

Our study is the first to explore this important public health issue by examining the relationship between immigrant household status and access to a medical home, insurance, and education services for children with ASDs and select DDs by using the data from the 2007 National Survey of Children's Health (NSCH) and the 2007 NSCH medical home composite measure. It is important to note that the definition of pediatric medical home has continually evolved over the years from the presence of an usual source of care and/or personal doctor/nurse to the American Academy of Pediatrics' definition that supports the availability of accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective medical care for infants, children, and adolescents.^{23,24} The 7 attributes of the American Academy of Pediatrics' definition are fully described elsewhere.²⁵ Our study further disaggregates the subcomponents of medical home to investigate the potential differences in perception and

expectation of the health care system of immigrant families with children with ASDs and select DDs.

METHODS

The data came from the 2007 NSCH, conducted by the Centers for Disease Control and Prevention's National Center for Health Statistics, with funding and direction from the Maternal and Child Health Bureau, Health Resources and Services Administration.²⁶ The 2007 NSCH addresses multiple aspects of children's health and well-being, including physical and mental health, health care, and social well-being, as well as aspects of the family and the neighborhood that can affect children's health on both the national and state levels.²⁷ The purpose of the survey was to provide national and state-specific prevalence estimates for a variety of children's health and well-being indicators. The 2007 NSCH was a telephone survey conducted between April 2007 and July 2008, with a total sample size of 91 642 children from birth through 17 years of age, including a sample of ~1800 children per state. A random-digit-dial sample of households with children <18 years of age was selected from each of the 50 states and the District of Columbia. One child was selected from all children in each identified household to be the subject of the survey. Interviews were conducted in English, Spanish, and 4 Asian languages: Mandarin, Cantonese, Vietnamese, and Korean. The respondent was the parent or guardian who knew most about the child's health status and health care. The interview completion rate was 66.0%. Methodological details of the survey are described elsewhere.²⁸ The National Center for Health Statistics Research Ethics Review Board approved all data collection procedures.

Children with ASDs and selected DDs were defined as children whose parent responded positively to questions

related to one of the following conditions: “Were you ever told by a doctor or other health care provider that [CHILD’s NAME] had autism, Asperger’s disorder, pervasive developmental disorder, or other autism spectrum disorder?”; and if yes, “Does [CHILD’s NAME] currently have autism or ASD?” ADHD or ADD was determined with the following question: “Has a doctor or other health care provider ever told you that [CHILD’s NAME] had Attention Deficit Disorder or Attention-Deficit/Hyperactivity Disorder, that is ADD or ADHD?” Learning disability was ascertained by the following question: “Does [CHILD’s NAME] currently have a learning disability?” Finally, any developmental delay was established by the following question: “Has a doctor or other health care provider ever told you that [CHILD’s NAME] has any developmental delay that affects [his/her] ability to learn?”

Variables

The major independent variable was immigrant household status. Immigrant households were defined as those with at least 1 foreign-born parent. Other variables used as covariates in the analyses included child’s age (3–5, 6–11, 12–17 years), gender, health insurance coverage, and household poverty status, measured as a ratio of federal poverty level in 4 categories (<100%, 100%–199%, 200%–399%, ≥400%). Health insurance coverage was reported as public, private, and no coverage in the bivariate analyses.

The major outcome of interest was the 2007 NSCH medical home composite measure, which is composed of 5 different subcomponent topics assessing the following: (1) child has at least 1 personal doctor or nurse; (2) family-centered care; (3) getting needed referral; (4) usual source(s) for care; and (5) effective care coordination.²⁹ The medical home construct was selected

because it contains the complex and long-term care coordination and cultural aspects of care that are of particular relevance to the care of immigrant children with ASDs and select DDs. The subcomponents were operationalized by using 1 or more survey questions. For family-centered care, the subcomponent was measured by parental response to the following 6 items: (1) whether provider spent enough time; (2) whether provider listened carefully; (3) whether provider was sensitive to family values and customs; (4) whether providers provided the needed information; (5) whether the provider helped you feel like a partner in the child’s health care; and (6) whether the family needed an interpreter to speak with the provider. The remaining 4 subcomponents of the medical home model are included in Table 2.

Statistical Analyses

To test differences between immigrant and non-immigrant households on select measures of access to medical home, health insurance coverage, and educational services, χ^2 analyses were used. The nonsignificant bivariate associations were not included in multivariable analysis. Multivariable logistic regression analyses were used to examine the associations between immigrant household status on access to medical home adjusting for children’s age and gender, family poverty level, and insurance coverage. Insurance coverage was dichotomized in the multivariable analyses as any or none. Adjusted odds ratios (ORs) and 95% confidence intervals (CIs) were computed by using the β coefficients and SEs obtained from the multivariable logistic analyses. To account for the complex sample design involving stratification, clustering, and multi-stage sampling of the NSCH, SAS version 9.1 (survey procs) (SAS Inc, Cary,

NC) was used to conduct the statistical analyses. Taylor series linearization methods were applied for variance estimation as recommended.²⁸

RESULTS

The final analytic sample of 413 children from immigrant households and 5411 children from nonimmigrant households were children with ASDs and select DDs whose parents responded positively to questions related to the conditions discussed in the Methods section. Table 1 summarizes the socio-demographic characteristics of children from both households and delineates the prevalence of ASDs and select DDs, as well as children with comorbidities. More than 70% of the children from immigrant households were Hispanic, whereas 59% of the children from nonimmigrant households were non-Hispanic white. Nearly 40% of children from immigrant households were from poor households compared with one-quarter of children from nonimmigrant households. For children aged 3 to 5 years, the proportion of children with ASDs and select DDs from immigrant households was twice that of non-immigrant households. A higher percentage of male children with ASDs and selected DDs was found in immigrant households.

Table 2 demonstrates differences between households within subcomponents of medical home, insurance coverage, and use of services. Under the subcomponent of receives effective care coordination, 69.3% of the parents from nonimmigrant households reported not receiving help with care coordination among health care providers as compared with nearly 50% reported by immigrant family households. However, 38.4% of immigrant households reported need for extra help in coordinating health care as opposed to 23.3% of nonimmigrant

TABLE 1 Socioeconomic and Demographic Characteristics of Children With ASDs and Select DDs by Immigrant Household Status

Characteristics (weighted percents)	Immigrant Households		Nonimmigrant Households		χ^2 P Value
	n = 413	SE	n = 5411	SE	
Prevalence of ASDs and select DDs in US children					<.0001
Prevalence of ASDs	0.4	0.12	1.0	0.08	
Prevalence of ADHD/ADD	2.2	0.33	6.3	0.20	
Prevalence of developmental delay	1.1	0.18	3.2	0.17	
Prevalence of learning disability	4.2	0.49	6.9	0.23	
Comorbidity of select DDs among children with ASD in US children					.86
Prevalence of ASD and ADHD	3.0	1.96	4.7	0.94	
Prevalence of ASD and developmental delay	11.5	8.5	1.5	2.98	
Prevalence of ASD and learning disabilities	78.8	9.7	73.5	3.38	
Prevalence of ASD only	6.7	3.8	11.4	1.78	
Weighted percents in children with ASDs and select DDs					
Child race/ethnicity					<.0001
Hispanic	71.1	4.44	14.9	1.56	
Non-Hispanic white	13.7	2.37	59.2	1.75	
Non-Hispanic black	9.1	3.87	19.9	1.43	
Non-Hispanic multirace/other	6.1	1.83	6.0	0.57	
Gender					.29
Female	29.7	4.98	35.4	1.67	
Male	70.3	4.98	64.6	1.67	
Household poverty level					.01
<100%	38.0	6.14	25.4	1.50	
100%–199%	29.8	6.41	24.1	1.52	
200%–399%	19.9	4.50	28.8	1.70	
400+%	12.3	2.29	21.7	1.52	
Child age, y					.02
3–5	15.4	4.72	6.6	0.81	
6–11	42.5	5.70	39.2	1.66	
12–17	42.1	6.03	54.2	1.71	
Maternal education					<.0001
Less than 12 y	52.5	5.45	21.0	1.39	
High school and beyond	47.5	5.45	79.0	1.39	
Primary language at home					<.0001
English	35.7	4.71	96.5	0.61	
Other	64.3	4.71	3.5	0.61	

Select DDs = ADHD/ADD, learning disabilities, and other developmental delay.
Source: The 2007 National Survey of Children's Health.

households. With respect to health care provider communication with child care providers, early intervention, education, and vocational programs, the percentages reported by immigrant and nonimmigrant households were similar at 39.2% and 40.8%, respectively. There were no significant differences with respect to education services.

Table 3 contains the adjusted ORs of selected measures of access to medical home and adequacy of health insurance coverage for children with

ASDs and select DDs, controlling for child's age and gender and household poverty status. Insurance coverage was also controlled for in all the access models. Children from immigrant households were more than 2 times as likely to not have a usual source of care (OR = 2.67, 95% CI = 1.32–5.4), and their parents were twice as likely to report physicians not spending enough time with them (OR = 2.1, 95% CI = 1.28–3.4). Immigrant families were also almost twice as likely to express need for extra help for health care coordination (OR =

1.78, 95% CI = 1.05–3.03) and more than 3 times as likely to lack any type of health care coverage (OR = 3.74, 95% CI = 1.89–7.4). However, immigrant families were less likely to report delayed/forgone care than nonimmigrant families (OR = 0.4, 95% CI = 0.23–0.68), and to report not receiving help in care coordination (OR = 0.49, 95% CI = 0.30–0.80). Insurance coverage was independently associated with all the outcomes, exerting significant and large effects. Household poverty status was also significant for all the models except for not receiving help and needing extra help with care coordination.

DISCUSSION

In this nationally representative sample, immigrant households were positively associated with reporting a lack of access to health insurance coverage, a usual source of care, sufficient clinician time, and needing extra help with health care coordination. In contrast, immigrant household status was negatively associated with reporting delayed/forgone care and not receiving help with health care coordination. Our findings on health insurance coverage and usual source of care are consistent with previous literature for CSHCN from immigrant families.³⁰ Immigrant families with children with ASDs and select DDs were less likely to report delayed/forgone care. This finding is also consistent with previous studies on children from immigrant families and may be attributable to unfamiliarity of parents from immigrant families with ASDs and select DDs diagnosis, medical treatments, and elective therapies not frequently covered by insurance (eg, applied behavior analysis, sensory integration therapy).¹⁶ Results of our study also indicate a paradox between delayed/forgone care and the lack of access to insurance coverage, usual source of care, and clinician's time.

TABLE 2 Medical Home, Insurance Coverage, and Educational Services Among Children With ASDs and select DDs by Immigrant Household Status (Unadjusted Analyses)

	Immigrant Household		Nonimmigrant Household		χ^2 P Value
	n = 413 %	SE	n = 5411 %	SE	
Access to medical home					
1. Child has at least 1 personal doctor or nurse					
Child has no personal doctor/nurse	17.1	4.86	7.5	0.93	.01
2. Receives family-centered care					
Providers do not spend enough time	51.2	5.95	28.4	1.53	<.001
Providers do not listen carefully	29.0	5.67	18.4	1.41	.04
Providers are not sensitive to family values and customs	30.7	5.33	16.9	1.35	<.01
Providers do not provide the needed information	38.9	5.72	24.0	1.55	.01
Providers do not help you feel like a partner in child's health care	33.2	5.76	19.9	1.48	.01
Families need interpreter to speak with provider	25.3	5.04	1.4	0.33	<.001
3. No problems obtaining referral					
Child needs a referral to see any doctors or receive any services	21.5	4.00	31.9	1.73	.03
Family has difficulty obtaining needed referrals	8.8	2.08	7.4	0.76	.51
4. Usual source of care					
Child has no usual source of care	17.7	4.64	6.1	1.03	<.001
Child receives care from hospital emergency department	3.9	1.54	2.9	0.65	.40
5. Receives effective care coordination					
Family does not receive help with care coordination among different health providers	49.8	5.94	69.3	1.59	<.001
Families need extra help in coordinating health care	38.4	5.97	23.3	1.58	.01
Families do not often receive help with coordinating health care	23.1	5.46	15.1	1.29	.10
Family dissatisfied with health care provider communication with other clinicians	8.5	4.38	7.7	1.14	.04
Health care providers need to communicate with child care, education, and vocational programs	39.2	5.98	40.8	1.65	.80
Family dissatisfied with provider communication with child care, education, and vocational programs	1.7	0.57	7.3	0.83	<.001
Insurance coverage and utilization of service					
Public insurance such as Medicaid or SCHIP	51.2	5.92	44.0	1.69	<.001
Private health insurance	27.2	4.19	48.6	1.74	
Not insured at time of interview	21.5	4.97	7.4	1.06	
Family pays money for health care beyond premiums	37.2	5.49	53.4	1.71	.01
Family reports delayed/foregone care	9.4	2.07	16.6	1.37	.01
Education services					
Has a written IFSP or IEP for developmental problems	5.5	1.73	5.1	0.72	.83
Families need provider to communicate with Early Intervention, Special Education, or Vocational Program	39.2	5.97	40.8	1.66	.80

IEP, Individualized Education Plan; IFSP, Individual Family Service Plan; SCHIP, State Children's Health Insurance Program. Source: The 2007 National Survey of Children's Health.

Cultural differences based on a combination of low expectations of the health care system and standard clinical care from immigrant family's countries of origin may play a role in parent perception. Past research has suggested that traditional beliefs and not medical insurance are significant predictors of delayed/foregone care for Asian American immigrant families.³¹

With regard to receiving help in coordinating care for their children, respondents answered 2 separate questions: (1) Did anyone help them arrange or coordinate care? and (2) Did they feel that they needed extra help in coordinating care? The results to these 2 questions highlight the particular constraints that immigrant parents often bring with them when attempting to navigate health care services in an

unfamiliar system, and often in an unfamiliar language. The adjusted OR indicated that immigrant parents were more likely to report receiving help in care coordination than nonimmigrant parents, and they were also more likely to report feeling a need for greater help. Consistent with expectations, immigrant parents, particularly those with limited English skills, are more likely to need and receive help (including interpreters) with making phone calls and medical appointments than non-immigrant parents, who not only speak English but are also more likely to be familiar with navigating their local health care systems. Immigrant parents' report of needing even more help than they received highlights the extent of help needed by these families in navigating often unfamiliar health care delivery systems. These results warrant further efforts to identify the specific types of extra help immigrant families most need, as well as to enhance the ability of providers to connect these families with other clinicians and to understand help-seeking patterns and expectations among immigrant families.

Some limitations of these analyses should be noted. The 2007 NSCH is a cross-sectional survey conducted in English, Spanish, and 4 Asian languages, with the screener being in English or Spanish. This may bias the non-English respondents toward those who are more educated and fluent in English, resulting in a likely underestimate of risk for the actual immigrant populations in the United States. Undocumented immigrants who may be at the highest risk for adverse health outcomes are likely not to participate in the survey because of fear of exposing their illegal status, even though the survey contained no information on citizenship status. This selection bias likely excluded the most underserved populations. The increased use of cell

TABLE 3 Adjusted ORs for Selected Dependent Variables Among Children From Immigrant Households With ASDs and Select DDs by Immigrant Household Status

	Lack Usual Source of Care		Expressed Need for Extra Help With Health Care Coordination		Lack of Clinician Time		Did Not Receive Help With Health Care Coordination		Delayed/Forgone Care		Lack of Health Insurance ^a	
	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI
Immigrant household status												
Immigrant	2.67	1.32–5.40	1.78	1.05–3.03	2.10	1.28–3.43	0.49	0.30–0.80	0.40	0.23–0.68	3.74	1.89–7.40
Nonimmigrant	1.00	ref	1.00	ref	1.00	ref	1.00	ref		ref	1.00	ref
Age, y												
3–5	1.00	ref	1.00	ref	1.00	ref	1.00	ref	1.00	ref	1.00	ref
6–11	1.51	0.56–4.04	0.92	0.51–1.66	1.48	0.85–2.60	1.25	0.76–2.04	1.37	0.79–2.38	1.19	0.46–3.10
12–17	1.39	0.54–3.57	0.62	0.34–1.13	1.34	0.80–2.37	1.26	0.78–2.05	1.25	0.72–2.17	3.19	1.19–8.50
Gender												
Male	1.00	ref	1.00	ref	1.00	ref	1.00	ref	1.00	ref	1.00	ref
Female	1.82	1.01–3.28	1.01	0.70–1.45	0.75	0.56–1.00	1.01	0.76–1.35	0.85	0.59–1.22	1.09	0.61–1.95
Household poverty status (ratio of family income to poverty threshold)												
Below 100%	2.72	1.51–4.91	1.64	0.96–2.80	4.70	3.07–7.24	0.89	0.57–1.39	2.30	1.35–3.94	5.11	2.48–10.49
100%–200%	2.53	1.15–5.59	1.61	0.94–2.73	2.70	1.69–4.30	0.63	0.40–1.00	1.97	1.12–3.47	7.21	3.11–16.75
200%–400%	2.97	1.54–5.71	1.45	0.82–2.57	2.07	1.33–3.23	1.02	0.66–1.58	1.42	0.73–2.76	3.16	1.48–6.71
At or above 400%	1.00	ref	1.00	ref	1.00	ref	1.00	ref	1.00	3.00	1.00	ref
Any type of health care coverage												
Yes	1.00	ref	1.00	ref	1.00	ref	1.00	ref	1.00	ref		N/A
No	4.02	1.78–9.12	1.21	0.67–2.18	2.54	1.53–4.20	0.63	0.37–1.07	2.58	1.55–4.32		

^a Model controls for child gender and age and household poverty status.

All other models control for child gender, age, and insurance coverage and household poverty status.

Source: The 2007 National Survey of Children's Health.

phones may also be introducing an additional source of bias for landline only surveys.^{32,33} In addition, Asians, who comprised nearly 5% of the US population in 2010, were only identified in the public use data files of this survey as part of the “other” group.

The study demonstrates that insurance coverage is an important factor in mitigating health care access barriers for immigrant households, while income also has strong independent

effects across different outcomes. The findings further elucidate important areas of deficits in the health care experiences of children with ASDs and select DDs from immigrant households. Public policy implications include increasing access to existing insurance programs, augmenting public awareness resources for ASDs and select DDs, and offering assistance to immigrant families that are struggling with the medical needs of their children.

Specifically, increased outreach and education to immigrant families may augment public awareness of available services and coverage. Improved insurance coverage will enable these children to enhance access to a usual source of care and to enhance care coordination. These joint efforts may build the capacity for immigrant families to advocate and pursue needed services within the medical home model.

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