

# Do Children with Autism Overutilize the Emergency Department? Examining Visit Urgency and Subsequent Hospital Admissions

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**Abstract** *Background* Children with autism spectrum disorders (ASD) are more likely to have difficulties accessing health care compared to other children with special health care needs. National data based on parent report indicate that children with ASD are overutilizing emergency department (ED) services, but data on actual ED use has been limited to children with psychiatric diagnoses. This study examined factors associated with ED utilization (rate, urgency, and hospital admissions) among children with ASD compared to those without ASD. *Methods* Data from an urban, tertiary children's hospital level 1 trauma center were examined retrospectively 2006–2009. Anderson's model of health services utilization served as the study framework. The NYU ED algorithm was used to predict nonurgent visits. Multivariate linear and logistic regression analyses were performed on the rate, urgency, and subsequent hospital admissions of these ED visits. *Results* There were 115,443 children 2–21 years old, accounting for a total of 157,902 visits. The top three reasons for visiting the ED for children with and without ASD were acute upper respiratory infections,

viral infections and otitis media. Children with ASD had on average 0.26 more ED visits annually than children without ASD ( $p < 0.01$ ) and were 2.6 % points more likely to have nonurgent visits;  $p < 0.01$ ). Their visits were also less likely to result in hospital admissions (OR 0.61;  $p < 0.01$ ). *Conclusions* Examination of predisposing, enabling, and reinforcing factors suggest that children with ASD were more likely to visit the ED and for nonurgent reasons.

**Keywords** Autism · Children · Emergency department · Hospital admissions · Overutilization · Nonurgent

## Significance

National data based on parent report indicate that children with autism spectrum disorders (ASD) are overutilizing emergency department (ED) services, but data on actual ED use has been limited to children with psychiatric diagnoses. Factors associated with ED utilization (rate, urgency, and hospital admissions) among children with ASD compared to those without ASD were examined. The top three reasons for visiting the ED were similar among those with ASD and those without ASD. Children with ASD were more likely to visit the ED than those without ASD and for nonurgent reasons.

## Introduction

Autism spectrum disorder (ASD) continues to be an important public health concern in the US, as the prevalence rate has increased to 14.7 per 1000 children (1 in 68) [1]. Compared to other children with special health care needs, children with ASD have higher physician and

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hospital utilization, and are more likely to have difficulties accessing health care [2, 3]. Children with a chronic condition such as ASD have consistently greater health care needs, which may increase the likelihood of emergency department (ED) overutilization [4–6]. Children with ASD experience a range of limitations in social interaction and functioning, stereotyped repetitive behaviors, language and speech impairments [7]. They may have one or more medical or behavioral comorbidities such as intellectual disabilities, higher rates of epilepsy, self-injurious behaviors, attention-deficit hyperactivity disorder, depression, and anxiety [8, 9]. Children with ASD may also have unmet needs and their families are more likely to experience financial, employment, and time burdens [10].

During the past decade, ED visits for children have increased to over 30 million annually [11]. The high number of ED visits has caused many EDs to reach the full limit of available and timely services, resulting in overcrowding, increased costs and uncoordinated care [12]. Many parental characteristics such as younger maternal age, lower educational levels and lower income levels have been identified as reasons for ED utilization [4, 13]. Previous interventions have been conducted to decrease the rate of ED utilization among frequent users; there is limited knowledge, however, about the rate of ED utilization among children with ASD and whether prevention efforts are needed [14]. The National Surveys of Children's Health and of Children with Special Health Care Needs, which are based on parent report, indicated that children with ASD are more likely to have greater ED use than children without ASD [5, 15]. There is a lack of comprehensive quantitative data on the reasons for which children with ASD are evaluated in the ED and whether there is an overutilization of services [4, 16, 17]. There is also a lack of data on whether children with ASD are more likely to have urgent ED visits and are more likely to be admitted to the hospital compared to children without ASD [18]. Evidence on frequency of ED use among children with ASD has been limited to those with psychiatric-related or injury-related ED visits [4, 16, 17, 19]. Previous research has also indicated that children with ASD are less likely to receive the comprehensive, coordinated, family-centered, and culturally effective health care that is representative of a medical home. [2, 3, 5, 20–24]. The purpose of this study was to thus investigate factors associated with the use of ED services (rate, urgency, and hospital admissions) among children with ASD compared to those without ASD. Andersen's Behavioral Model of Health Services Utilization was used as the study framework [25]. We hypothesized that predisposing factors, enabling factors, and perceived need for ED services differed among children with ASD and children without ASD, and were associated with the rate and urgency of ED visits, and hospital admissions.

## Methods

### Study Design and Setting

A retrospective analysis of 2006–2009 administrative ED discharge data was conducted. Data were collected from a large, urban, tertiary children's hospital that has one of the largest Level 1 Pediatric Trauma Centers in Southern California and the Western United States, with over 65,000 annual ED visits per year. ED records were examined for patients 2–21 years old, with and without an ASD diagnosis. The hospital institutional review board approved this study prior to data collection.

### Theoretical Framework

Andersen's Behavioral Model of Health Services Utilization was used as the study framework [25]. The model, used in previous ED studies, proposes that predisposing factors (sociodemographics), enabling factors (family and community resources), and perceived need (individual, social, clinical needs) affect health behavior in terms of personal health practices and use of health services [17, 26, 27]. We aimed to examine the outcomes rate and urgency of ED visits and hospital admissions, as a higher rate of visits may be associated with perceptions of greater urgency. Furthermore, if children with ASD were more likely to be admitted to the hospital, this would demonstrate that perceptions of urgency among children with ASD were more accurate.

### Study Measures

#### *Predisposing Factors*

These included age, gender, and race/ethnicity. All variables were calculated based on unique, de-identified medical record numbers, which ensured that we did not double-count children who came to the ED for more than one visit. Age was categorized as: early childhood (2–5 years), childhood (6–11 years), adolescence (12–17 years), and young adulthood (18–21 years). We excluded children younger than 2, considering a definitive ASD diagnosis could be made as early as 18 months. Race/ethnicity was defined as Hispanic, African American/Black, Asian, White, or other.

#### *Enabling Factors*

These included the variables primary language and insurance. Primary language was English or Spanish. Insurance status was categorized as public insurance, including Medicaid managed care (with a specific health plan and provider) and Medicaid fee-for-service (without a designated plan or provider), private insurance, or no insurance.

### Perceived Need

Perceived need included the variables: time of arrival and distance from hospital. The time of arrival to the ED was categorized by weekday hours (Monday to Friday, 8:00 am to 4:59 pm), evening/weekend hours (Monday to Friday, 5:00 pm to 9:59 pm and weekends from 8:00 am to 9:59 pm), and late night/early morning hours (daily from 10:00 pm to 7:59 am). Parents may have a high perceived need for ED care if they visit the ED with their children during weekday hours when there are a greater number of options for care. Patient zip code was used to calculate distance traveled in miles to the hospital from the child's residence. The use of zip codes also was used as a proxy for how far families were willing to travel to meet the perceived need for ED services.

### ASD and Other Diagnoses

ASD, the primary independent variable, and other medical diagnoses were identified by ICD-9-CM codes. Similar to other ASD studies using billing diagnoses, specific diagnoses included: autistic disorder, childhood disintegrative disorder, pervasive developmental disorder not otherwise specified, and Asperger syndrome (299, 299.x, and 299.xx). A visit was considered an ASD-related visit if it was from a child that has had at least one visit that included an ASD-related diagnosis from 2006 to 2009. Given the emergent nature of the ED visits, it was not feasible for ED physicians to use standardized assessment procedures to identify ASD in these children.

### Outcome Measures

Three outcome variables were used to characterize ED visits: rate of ED visits, urgency of ED visits, and odds of hospital admissions; rate of visits was examined at the person level, while urgency of ED visits and odds of hospital admissions were examined at the visit level. Investigating all three outcomes allowed for exploration of both the utilization patterns and the urgent nature of these ED visits.

**Rate of ED Visits** This outcome indicated a child's reliance on emergency medicine for sick care. This was measured as the number of ED visits per child per year.

**Urgency of ED Visit** The NYU ED algorithm was used to categorize ED visits to determine the level of urgency among children with ASD [28]. The algorithm uses ED administrative discharge data to calculate the probability of whether an ED visit is urgent or nonurgent using International Classification of Diseases, 9th Revision, Clinical Modification (ICD-9-CM) Codes. Nonurgent ED visits were defined as

nonurgent or primary care treatable, meaning that immediate medical care was not required within 12 h based on the patient's initial complaint, presenting symptoms, vital signs, medical history, or that the treatment was needed within 12 h, but could have been provided in a primary care setting. Urgent ED visits were defined as visits needing ED care within 12 h due to the complaint, procedures, or resources used [28]. The outcome of nonurgent visit is constructed as the probability/risk of this visit being nonurgent, which ranges between 0 and 100 %. ED visits involving injury, psychiatric, substance abuse or alcohol-related diagnoses were excluded from the analyses for urgency of visits only, as the ED algorithm does not classify these conditions; they were however, included in the analyses for rate of visits and hospital admissions.

**Hospital Admissions** A hospital admission resulting from an ED visit indicated the acuteness of a visit. This was measured as a dichotomous variable (yes or no).

### Data Analysis

Summary statistics were produced to describe the study population and to determine if there were any outliers or missing data. Bivariate analyses were conducted to examine differences in children with and without ASD. Multivariate linear regression was conducted for the outcome rate of ED visits per child per year, and for the outcome of whether an ED visit was categorized as nonurgent. Multivariate logistic regression was also conducted to determine whether an ED visit resulted in hospital admission. Multivariate linear and logistic regression models were adjusted using robust variance estimators. STATA version 11 software was used for the analyses.

## Results

### Differences in Visits by Predisposing Factors, Enabling Factors, and Perceived Need

There were a total of 157,902 ED visits by 115,443 children 2–21 years of age. There were 1424 children with ASD, accounting for 2426 visits (Table 1). Independent samples t-tests indicated significant differences among children with and without ASD for most predisposing factors, enabling factors and for perceived need for ED services. Children with ASD who utilized the ED were older; most visits were from 6 to 11 year-olds (38.7 %), while among children without ASD most visits were from children 2 to 5 years of age (44.8 %). There were fewer females in both groups: 15.7 % of visits from children with ASD were from females, which was expected, given the

**Table 1** Differences in visits among children with and without ASD by predisposing factors, enabling factors, and perceived need

Characteristics	Visits from children with no ASD (n = 155,476) n (%) or mean (SD)	Visits from children with ASD (n = 2426) n (%) or mean (SD)	t	p
<i>Predisposing factors</i>				
<i>Age group</i>				
2–5	69,617 (44.8)	944 (38.9)	5.7	<0.01
6–11	48,964 (18.7)	998 (38.7)	−10.1	<0.01
12–17	33,175 (13.6)	437 (16.9)	4.9	<0.01
18–21	3720 (1.5)	47 (1.8)	1.2	0.15
<i>Gender</i>				
Female	71,455 (46.0)	380 (15.7)	29.8	<0.01
<i>Race/ethnicity</i>				
Hispanic	118,865 (76.5)	1690 (69.7)	7.8	<0.01
Black/African American	12,716 (8.2)	203 (8.4)	−0.3	0.74
Asian	7533 (4.9)	187 (7.7)	−6.5	<0.01
White	5028 (3.2)	153 (6.3)	−8.4	<0.01
Other	11,334 (7.3)	193 (8.0)	−1.3	0.21
<i>Enabling factors</i>				
<i>Primary language</i>				
English	70,637 (45.4)	1252 (51.6)	−6.1	<0.01
<i>Insurance status</i>				
Public insurance	121,277 (78.0)	2083 (85.9)	−9.3	<0.01
Medicaid MC	92,308 (59.4)	1015 (41.8)	17.4	<0.01
Medicaid FFS	28,478 (18.3)	1063 (43.8)	−32.1	<0.01
Private insurance	20,827 (13.4)	273 (11.3)	3.1	<0.01
No insurance	13,372 (8.6)	70 (2.9)	10.0	<0.01
<i>Perceived need</i>				
<i>Time of arrival</i>				
Late night/early morning	36,376 (23.4)	531 (21.9)	1.7	0.08
Weekday hours	50,363 (32.4)	889 (36.7)	−4.4	<0.01
Weekday evening/weekend hours	68,737 (44.2)	1006 (41.5)	2.7	<0.01
Distance to hospital (m)	8.0 (8.9)	7.9 (8.2)	0.6	0.55

MC managed care, FFS fee-for-service, m mile

disproportion of males with ASD, while 46 % of visits were from females without ASD. In addition, 69.7 % of visits were from Hispanic children with ASD, and 76.5 % were from Hispanic children without ASD. Children with ASD were significantly more likely to have public insurance (Medicaid managed care or Medicaid fee-for-service) (85.9 vs. 78 %), and to arrive during weekday hours (36.7 vs. 32.4 %) compared to children without ASD.

**Multivariate Outcomes: Rate and Likelihood of Nonurgent ED Visits**

Controlling for predisposing factors, enabling factors, and perceived need for ED services, children with ASD had

0.26 more visits to the ED per year ( $p < 0.01$ ) and were 2.6 % points ( $p < 0.01$ ) more likely to have nonurgent ED visits than children without ASD (Table 2). *Predisposing factors*: Older age and non-Hispanic children were associated fewer ED visits and a lower likelihood of nonurgent visits. *Enabling factors*: Children with a private insurance or no insurance had lower rates of ED visits, and were less likely to have nonurgent visits. *Perceived need for ED services*: Time of arrival during weekday hours and weekday evening/weekend hours or during times when many primary care providers or urgent care sites are available, compared to late night/early morning hours, was associated with lower rates of ED visits, and a greater likelihood of nonurgent visits.

**Table 2** Multivariate regression outcomes: rate and urgency of emergency department visits

	Annual rate of ED visits (n = 115,443)		Nonurgent visits (n = 118,096)	
	$\beta$	<i>p</i>	Percentage points	<i>p</i>
Autism spectrum disorder (reference group = no ASD)	0.26	<0.01	2.6	<0.01
<i>Predisposing factors</i>				
Age group, y (reference group = 2–5)				
6–11	–0.16	<0.01	–2.6	<0.01
12–17	–0.17	<0.01	–5.5	<0.01
18–21	–0.03	0.27	–8.6	<0.01
Gender (reference group = male)				
Female	–0.01	0.07	1.7	<0.01
Race/ethnicity (reference group = Hispanic)				
White	–0.03	0.12	–5.2	<0.01
Asian	–0.09	<0.01	–3.3	<0.01
Black/African American	–0.02	0.13	–0.8	<0.02
Other	–0.12	<0.01	–1.0	<0.01
<i>Enabling factors</i>				
Primary language (reference group = Spanish)				
English	0.05	<0.01	1.3	0.47
Insurance status (reference group = Medicaid MC)				
Medicaid FFS	0.22	<0.01	–4.8	<0.01
Private Insurance	–0.06	<0.01	–3.4	<0.01
No insurance	–0.20	<0.01	–1.3	<0.01
<i>Perceived need</i>				
Time of arrival (reference group = late night/early morning)				
Weekday hours	–0.04	<0.01	2.0	<0.01
Weekday evening/weekend hours	–0.05	<0.01	0.6	<0.01
Distance to hospital, m	–0.00	0.01	–0.1	<0.01

$\beta$  beta value, MC managed care, FFS fee-for-service, m mile

### Top ED Discharge Diagnoses

Children with ASD had typical, routine illnesses similar to children without ASD.

The top three reasons for visiting the hospital ED were the same for children with and without ASD: acute upper respiratory infections were the most common diagnosis (465.9), followed by viral infections (079.99) and otitis media (382.9) (Table 3). About 9 % of children with ASD were also seen for convulsions and about 4 % of children with ASD were diagnosed with head injury (unspecified). Other major diagnoses were similar among the two groups of children. Over 90 % of the top ten diagnoses were classified as primary care treatable among all children. Children with ASD also had high percentages of primary care treatable classifications for their top three diagnoses: acute upper respiratory infections (97.6 %), viral infections (92.6 %), and otitis media (91.6 %).

### Multivariate Outcomes: Hospital Admissions

Children with ASD had lower odds of being admitted to the hospital from the ED, compared to those without ASD, controlling for predisposing factors, enabling factors, and perceived need for ED services, (OR 0.61;  $p < 0.01$ ) (Table 4). *Predisposing factors*: Children who were 6 years of age and above and were non-Hispanic had significantly greater odds of being admitted to the hospital, while females had significantly lower odds of being admitted. *Enabling factors*: Children with a primary language of English had significantly lower odds of being admitted to the hospital; children with Medicaid fee-for-service or private insurance, compared to those with Medicaid managed care, had significantly greater odds of being admitted to the hospital. *Perceived need for ED services*: Time of arrival to the ED during weekday and weekday evening/weekend hours, compared to late night/early morning hours, was significantly associated with

**Table 3** Top ten principal diagnoses upon emergency department discharge

No autism spectrum disorder			Autism spectrum disorder		
n (%)	ICD-9	Principal diagnosis	n (%)	ICD-9	Principal diagnosis
n = 54,206 (34.9)			n = 915 (37.7)		
10,668 (6.9)	79.99	Viral infection	189 (7.8)	465.9	Upper respiratory infection (acute)
10,407 (6.7)	465.9	Upper respiratory infection (acute)	166 (6.8)	079.99	Viral infection
7856 (5.1)	382.9	Otitis media	152 (6.3)	382.9	Otitis media
4356 (2.8)	787.03	Vomiting	82 (3.4)	780.39	Convulsions
4212 (2.7)	493.02	Asthma	73 (3.0)	787.03	Vomiting
3946 (2.5)	789	Other symptoms involving abdomen and pelvis	59 (2.4)	564.00	Constipation
3345 (2.2)	486	Pneumonia	55 (2.3)	486	Pneumonia
3204 (2.1)	462	Acute pharyngitis	53 (2.2)	493.02	Asthma
3126 (2.0)	599	Urinary tract infection	48 (2.0)	959.01	Head injury, unspecified
3086 (2.0)	558.9	Noninfectious gastroenteritis and colitis	38 (1.6)	558.9	Noninfectious gastroenteritis and colitis

Principal diagnosis was the first diagnosis listed in the ED administrative record. ICD-9: *International Classification of Diseases, Ninth Revision*

**Table 4** Multivariate regression outcomes: emergency department visits resulting in hospital admissions (n = 157,902)

	OR	p
Autism spectrum disorder (reference group = no ASD)	0.61	<0.01
<i>Predisposing factors</i>		
Age group, y (reference group = 2–5)		
6–11	1.47	<0.01
12–17	1.74	<0.01
18–21	2.36	<0.01
Gender (reference group = male)		
Female	0.95	0.02
Race/ethnicity (reference group = Hispanic)		
White	2.02	<0.01
Asian	1.29	<0.01
Black/African American	0.98	0.59
Other	1.10	<0.02
<i>Enabling factors</i>		
Primary language (reference group = Spanish)		
English	1.10	<0.01
Insurance status (reference group = medicaid MC)		
Medicaid FFS	6.89	<0.01
Private Insurance	2.91	<0.01
No insurance	0.09	<0.01
<i>Perceived need</i>		
Time of arrival (reference group = late night/early morning)		
Weekday hours	0.14	<0.01
Weekday evening/weekend hours	0.33	<0.01
Distance to hospital (m)	1.03	<0.01

OR odds ratio, MC managed care, FFS fee-for-service, m mile



lower odds of being admitted to the hospital. Those who traveled a greater distance to the hospital ED had significantly greater odds of being admitted to the hospital.

## Discussion

To our knowledge, this study is among the first to examine factors associated with ED use among children with ASD, and not just those who had psychiatric-related or injury-related ED visits. In the present study, children with ASD had a higher rate of nonurgent ED visits, compared to visits among children without ASD. Children with ASD also had lower odds of hospital admissions than children without ASD, indicating that many of the ED visits may have been preventable or avoidable. Various predisposing factors, enabling factors, and perceived need for ED services impacted health behavior, as they were associated with the rate and urgency of ED visits, and hospital admissions among children with ASD compared to children without ASD. The likelihood of having a nonurgent visit due to ASD was a larger effect than gender, though it was smaller than some of the age and race/ethnicity effects. In addition, the odds of being admitted to the hospital were lowest for those with no insurance, those who arrived to the ED during weekday business hours or weekday evening/weekend hours compared to late night/early morning hours, and among children with ASD. Other researchers examining national samples of pediatric ED visits have noted similar associations [17, 19, 29]. We did not find any published values for clinical meaningfulness pertinent to ED utilization among children with ASD. Parents of children with ASD may be accessing costly services to seek treatment during hours when many primary care providers are available for common childhood illnesses, which do not typically require emergency care or result in hospital admissions. The higher rates of nonurgent visits among children with ASD could present challenges for treating children with urgent conditions in a timely manner, contributing to overcrowding and uncoordinated care [12, 30].

Research has indicated that children with ASD have limited access to a medical home, which may have led to the greater rate of nonurgent ED visits and lower odds of hospital admissions among children with ASD [20–24]. In terms of the top ten principal diagnoses for children with and without ASD, the majority were categorized as primary care treatable, meaning that immediate medical care was not required within 12 h or that the treatment was needed within 12 h, but could have been provided in a primary care setting. While most diagnoses among children were similar in both groups, the 9 % of convulsions among children with ASD may have been due to epilepsy, a common comorbidity highly associated with ASD [8].

Among the 4 % of children with ASD diagnosed with head injury (unspecified), this was possibly related to the behavioral challenges often observed among these children. A lack of coordination between providers, patients, and families is associated with fewer positive health behaviors, decreased adherence to recommended treatments, and decreased access to care [31]. Parent perceptions of primary care providers may also contribute to increased use of the hospital ED. Compared to other parents of children with special health care needs, parents of children with ASD are less likely to be satisfied with their children's health care [3]. Some parents have indicated that primary care providers have a limited role in the management of their children's care [5]. A study examining ED use among children with developmental disabilities, including autism, from the National Survey of Children with Special Health Care Needs, indicated that children who had more frequent ED use did not have providers who listened to parental concerns, did not have strong family partnerships with their providers, and did not have culturally competent providers [23]. Parents may utilize their primary care provider for routine, non-acute visits, but may have less confidence in their primary care provider's ability to manage problem behaviors or acute health issues, opting for ED services instead [2, 5]. Educating parents of children with ASD about the benefits of a medical home, thus may play an important part in decreasing nonurgent ED use.

A potential study limitation was that a comparison group was used instead of a control group, as it was not possible to randomize ASD and non-ASD groups. The diagnosis of ASD was made by using ICD-9-CM billing codes that were assigned by ED physicians after patient encounters. ED physicians did not use standardized assessment procedures to identify ASD, which may underestimate ASD prevalence rates. Given that this was a retrospective study, it was also not possible to validate whether the children had a primary care physician in the community and access to a medical home, if the families had tried to access a community primary care physician before coming to the ED, or if the visit was the result of a 911 emergency call. As indicated, the NYU-ED classification algorithm excluded injury-related, psychiatric-related, and substance abuse-related visits, which may underestimate the urgency data among children with ASD; psychiatric-related or injury-related visits, including self-injurious behavior, comprise about 1.2–5 % of all pediatric ED visits [32–34]. While the present study excluded psychiatric, substance-related and injury-related ED visits for the multivariate analyses on urgency, they were not excluded from the other multivariate analyses on visits and hospital admissions. We were also unable to observe children who did not utilize the ED; therefore we could not draw conclusions on utilization

rates of the general population. Finally, the use of pediatric administrative ED discharge data from one of the largest Level 1 Pediatric Level Trauma centers, in Southern California and the Western United States, allowed for a large sample size and provided objective quantitative measures. However, the data we employed may not be representative of pediatric EDs serving non-Hispanic children with ASD in non-urban areas.

## Conclusions

On average, medical expenditures for children with ASD are 4.1–6.2 times greater than for those without ASD [18, 35]. High demand for ED services contributes to fragmented care, increased costs, and overcrowding. Educating parents of children with ASD about the benefits of a medical home, increasing training for providers who are caring for children with ASD, and improving parent-provider communication in primary care settings may help reduce nonurgent, frequent ED use among children with ASD. The findings may ultimately help inform policies to better address the needs of children with ASD and improve continuity of care for these families.

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