It is illegal to post this copyrighted PDF on any website. Youth With Autism Spectrum Disorder in the Emergency Department

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ABSTRACT

Objective: This comprehensive literature review summarizes reports on emergency department (ED) use by youth with autism spectrum disorder (ASD).

Data Sources: We conducted a systematic search of the PubMed, PsycINFO, CINAHL, and EMBASE databases (1985–2016), limited to studies published in English. The following search terms were used: *autism, autistic, Asperger, emergency department/room/physician/doctor/ treatment/medicine, childhood developmental disorders* (*pervasive*), and *emergencies*.

Study Selection: Our search found 332 articles, of which 12 specifically addressed ED services in ASD youth.

Data Extraction: Abstracts or full text articles were reviewed for relevance. Case reports, review articles, and studies that reported on adults only or that included youth and adults but did not stratify results by age were excluded.

Results: Youth (aged 0–17 years) with ASD were up to 30 times more likely to present to the ED than youth without ASD. Individuals with ASD who visited the ED were older, more likely to have public insurance, and more likely to have nonurgent ED visits. For youth with ASD, up to 13% of visits were for behavioral or psychiatric problems, whereas for youth without ASD less than 2% were for psychiatric problems. ASD youth were more likely to present for externalizing problems or psychotic symptoms. Youth with ASD were also likely to have repeat visits to the ED and more likely to be admitted to a psychiatric unit or medical floor than youth without ASD.

Conclusions: This review found significant gaps in the literature related to ED service use by youth with ASD. More research is needed to avoid unnecessary ED utilization and hospitalization, reduce medical costs, and improve outcome for youth with ASD.

J Clin Psychiatry 2018;79(3):17r11506

To cite: Lytle S, Hunt A, Moratschek S, et al. Youth with autism spectrum disorder in the emergency department. *J Clin Psychiatry*. 2018;79(3):17r11506.

To share: https://doi.org/10.4088/JCP.17r11506 © Copyright 2018 Physicians Postgraduate Press, Inc.

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*Corresponding author: Sarah Lytle, MD, Department of Psychiatry, W. O. Walker Bldg, 10524 Euclid Ave, Ste 1155A, Cleveland, OH 44106 (sarah.lytle@uhhospitals.org). A utism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by 2 major domains of impairment: (1) deficits in social communication and social interaction and (2) restricted, repetitive patterns of behavior, interests, and activities.¹ A systematic review of epidemiologic studies of ASD found a global prevalence of 7.6 per 1,000 (1 in 132) in 2010,² and the prevalence of ASD in the United States is 1 in 68 children.³ Services for youth with ASD can be expensive, difficult to obtain, or simply unavailable to those who need them most.

Autism spectrum disorder confers a risk for behaviors that can be challenging and can lead caregivers to seek intervention from medical and mental health professionals. Children and adolescents with ASD often struggle with a number of associated conditions and problems that drive health care utilization throughout their lives. Intellectual disability, comorbid in 45% to 60% of children with ASD, is a predictor of greater ASD severity and confers additional significant risks for physical and mental health issues.^{4,5} Children and adults with ASD comorbid with intellectual disability have also been found to have significantly higher levels of maladaptive behaviors including self-injury, aggression, and disruption to the environment.⁶ Children with ASD also experience a higher rate of comorbid mental health problems including attention-deficit/ hyperactivity disorder (ADHD) and behavioral, adjustment, anxiety, impulse control, and mood disorders than those without ASD.^{7,8} Furthermore, deficits in social-emotional reciprocity and verbal and nonverbal communication, inflexibility related to environmental changes and routines, difficulties with transitions and change, and hyper-reactivity to sensory stimuli can all lead to behavioral exacerbations, such as irritability, aggression, and self-injury, in youth with ASD.

While initial management of mental health concerns for those with ASD is typically done in the outpatient setting, parents of youth with ASD often report unmet needs for their children with ASD. For example, surveys of parents in the outpatient setting have indicated that they need more information about availability of services, access to these services, guidance on how to handle their child's challenging behaviors in the home, and continuity of support rather than relying on acute interventions in times of crisis.^{9–11} Approximately 30% of parents report that their child's developmental needs are still not being met by their current treatment.¹² In situations where the child's behavior or mental health needs are too severe or acute to manage in the outpatient setting or in the home, the individual may require emergency services and be taken to the ED for acute management and interventions.

Children and families living with autism use the ED to manage crises related to a variety of factors. Having a clear understanding of precipitants to ED use, apparent unaddressed needs that lead

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- Having a clear understanding of precipitants to emergency department (ED) use, unaddressed needs that lead to ED use, and how ED services are implemented to manage children with autism spectrum disorder (ASD) in crisis could help to inform and assist ED staff and ambulatory service providers to better meet the needs of individuals with ASD and their families.
- Identifying gaps in service provision through screening, education, and referral may help decrease the number of unnecessary ED visits for youth with ASD.

Figure 1. Search Parameters for Emergency Department (ED) Use by Youth With Autism Spectrum Disorder (ASD)



to ED use, and how ED services are implemented to manage children with ASD in crisis could help inform and assist both ED staff and standard ambulatory service providers to better meet the needs of individuals with ASD and their families. This systematic review of the published English literature summarizes original research findings on ED utilization by youth with ASD. Findings can inform treatment planning and identify gaps in current knowledge.

METHODS

We conducted a systematic search of the PubMed, PsycINFO, CINAHL, and EMBASE databases (1985–2016). The following keywords were used as our search terms: *autism, autistic, Asperger, childhood developmental disorders (pervasive), emergency department, emergency room, emergency physician, emergency doctor, emergency treatment, emergencies, and/or emergency medicine.*

The results (either abstracts or full text articles) were retrieved and reviewed for relevance. The reference lists of relevant publications were hand searched for relevant articles. We included all studies published in English that reported on ED use by youth with autism (Figure 1). Case reports, review articles, and studies that reported on adults only or that included youth and adults but did not stratify results by age were excluded.

Our search found 332 articles of which 12 were found to be relevant and specifically addressed ED services in youth with ASD (Table 1).7,8,13-22 These studies included 2 retrospective chart reviews of youth with ASD in tertiary care pediatric centers, a retrospective cohort study of all patients who presented to an urban teaching hospital over a 1-year period, 8 database analyses (including state and national databases), and a parent survey. All studies, except a database analysis done in Taiwan²² and a retrospective chart review done in Canada,16 were conducted in the United States. The pertinent studies were conducted between 2000 and 2012 and published between 2006 and 2015. Six were published in autism or developmental disability journals, 4 were published in pediatric journals, and 2 were published in pediatric emergency medicine journals. The studies reported on youth from infancy to 24 years old. In all studies, the majority of youth with ASD were boys, with the percentage of girls in the studies ranging from 13% to 39%. While 7 studies did not report on race or ethnicity of the sample population, the 5 studies that did reported considerable heterogeneity in terms of race and ethnic representation (Figure 2).

A comparison of characteristics of ED use in children with ASD versus children without ASD is detailed in Tables 2 and 3. Six studies did not report on the actual number of youth with ASD who visited the ED, but instead reported on the percentage of ED visits by youth with and without ASD. Six articles, including 4 retrospective studies, reported on frequency of ED use by youth with ASD compared to youth without ASD. First, a retrospective database analysis of children and adolescents aged 0-17 years reported that children with ASD were 1.12 times more likely to visit the emergency room than children without ASD and that the mean number of annual ED visits was 0.29 versus 0.25, respectively.²² The mean number of ED visits in youth with and without ASD was 0.18 versus 0.10, respectively, in a cross-sectional analysis of the 2003-2004 National Survey of Children's Health.⁸ Another retrospective study identified ED and inpatient hospitalization records for 252 youth aged 9 to 18 years with ASD from January 2009 to December 2010, 50% of which were also identified as having

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Table 1. Results of Comprehensive Review of Youth With Autism Spectrum Disorder (ASD) in the Emergency Department (ED)									
			No. of Individuals	Age Range	% Girls				
Study	Methodology	Time Period	With:Without ASD	(mean age), y	With ASD				
Casey et al (2015) ¹⁵	Retrospective chart review	2007-2012	36:36	18 months-18 (6.4)	39				
Cohen-Silver and Muskat (2014) ¹⁶	Retrospective chart review	2011	130:0	6–17 (12)	21				
Croen et al (2006) ⁹	Retrospective database analysis	July 2003–June 2004	3,053:30,529	2–18	19				
Deavenport-Saman et al (2016) ¹⁷	Retrospective analysis of ED discharge data	2006-2009	1,424:115,443	2–21	15.7				
Gurney et al (2006) ¹⁰	Cross-sectional analysis of National (telephone) Survey of Children's Health	2003-2004	324,000:61,100,000	3–17	21				
lannuzzi et al (2015) ¹⁸	Nationwide Emergency Department Sample database review	2010	*	0–19	20.9				
Kalb et al (2012) ¹⁹	National Emergency Department Sample cross-sectional, observational study	2008	*	3–17	17.8				
McDermott et al (2008) ²⁰	Medicaid eligibility and claims data	2003	1,610:92,000	1–17	19.2				
McDermott et al (2015) ²¹	Population-based cross-sectional database study	2000-2010	*	15–24	23.7				
Schlenz et al (2015) ²²	Retrospective database analysis	2009-2010	252:1,260	9–18	16.7				
Wharff et al (2011) ²³	Retrospective cohort study	July 2007–June 2008	*	*	*				
Wu et al (2014) ²⁴	Retrospective database analysis	2008	3,280:9,840	0–17	13.3				
*Data not reported.									



^aSchlenz et al,²² Deavenport-Saman et al,¹⁷ Gurney et al,¹⁰ McDermott et al,²¹ and Casey et al.¹⁵ ^bFor Casey et al,¹⁵ ethnicity was reported separately from race, with 8% of study population

intellectual disability.²⁰ A comparison group of demographically similar youth was used. In this study, youth with ASD were found to be greater than 5 times more likely to have an ED visit or inpatient hospitalization as compared to youth without ASD.²⁰ A third retrospective analysis of children enrolled in the Kaiser Permanente Medical Care Program in California from July 2003 to June 2004 (aged 2-18, mean age 10 years) reported that the average number of ED encounters was 30% higher for youth with ASD than youth without ASD and that ED costs were 30% higher.⁷ Finally, a retrospective analysis of ED discharge data including 115,443 youth aged 2-21 years (including 1,424 children with ASD) reported that children with ASD who visited the ED were older (38.7% of visits were from 6- to 11-year-olds) as compared to children without ASD (44.8% of visits were from 2- to 5-year-olds).¹⁵ Children with ASD were also significantly more likely to have nonurgent ED visits ("meaning that immediate medical care was not required within 12 hours based on the patient's initial complaint, presenting symptoms, vital signs, or medical history or that the treatment was needed within 12 hours, but could have been provided in a primary care setting")¹⁶ and had 0.26 more ED visits per year than those without ASD.15

Two other studies also reported on ED use by youth with ASD. In a telephone survey study, which included 85,272 interviews, parents of children with ASD reported significantly more visits to a physician or hospital (including ED visits) for their child in the previous 12 months than parents of children without ASD.⁸ Additionally, a population-based cross-sectional database study reported that the adjusted rates of ED visits for adolescents with autism (21.1%) were higher than the rates for an unaffected comparison group (13.7%).¹⁹

Six studies reported on reasons for ED visits for youth with and without ASD. A cross-sectional, observational study was done to examine the prevalence and characteristics of psychiatry-related ED visits for youth with ASD (diagnoses included autistic disorder, childhood disintegrative disorder, and pervasive developmental disorders).¹⁷ In this study, 12.9% of ED visits for youth with ASD were for psychiatric problems, whereas only 1.75% of ED visits for youth without ASD were for psychiatric problems.¹⁷ Emergency department visits for children with ASD as compared to children without ASD were more likely to be for externalizing problems (42.1% in those with ASD versus 22.4% in those without ASD) or psychotic disorders (7.8% versus 4.4%, respectively) than other psychiatric problems, including anxiety (10.8% in those with ASD versus 21.8% in those without ASD) or mood disorders (36.9% versus 48.5%, respectively). Rates of suicide attempts or self-injurious behavior were similar in those with and without ASD (2.3% versus 2.9%).¹⁷ However, in another

Figure 2. Reported Racial Demographics of Youth With Autism Spectrum

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being reported as Hispanic.

Table 2. Comparison of Emergency Department (ED) Visit Characteristics in Children With Autism Spectrum Disorder (ASD) Versus Without ASD

Characteristics	With ASD	Comparison Without ASD	Source
Rate of presentation to ED	1.12× more likely (SD = 1.05–1.18) 0.26 more visits/year 21.1%	Reference Reference 13.7%	Wu ²⁴ Deavenport-Saman ¹⁷ McDermott ²¹
Mean ED visits per capita (visits/year)	0.29±0.52 0.16 0.18 (Cl, 0.12–0.23)	0.25±0.46 0.12 0.10 (Cl, 0.09–0.10)	Wu ²⁴ Croen ⁹ Gurney ¹⁰
Length of ED stay (mean time in hours)	1.209	No difference	Casey ¹⁵
Financial characteristics			
Public insurance	86%	78%	Deavenport-Saman ¹⁷
ED visit costs (mean)	\$67 (P=.0001)	\$52	Croen ⁹
Repeat visit in past month (frequency %)	25% 50% of revisits in 1–15 days	No comparison	Cohen-Silver ¹⁶
Disposition			
Psychiatric hospitalization	Preadolescent: RR = 10.32 (3.35–31.78) (P<.001) Adolescent: RR = 9.51 (3.53–26.39) (P<.001)	Reference	Schlenz ²²
Mean duration of hospitalization (days)	1.46, SD=11.32 (P<.001)	0.21, SD = 1.35	Wu ²⁴
Total hospitalization	OR=0.61 (P<.01) Preadolescent: RR=2.39 (1.24–4.61) (P=.009) Adolescent: RR=3.44 (1.83–6.46) (P=.001)	Reference Reference Reference	Deavenport-Saman ¹⁷ Schlenz ²² Schlenz ²²
Medical hospitalization	Preadolescent: RR = 1.30 (0.57–2.98) (<i>P</i> = .533) Adolescent: RR = 1.85 (0.85–4.01) (<i>P</i> = .119)	Reference Reference	Schlenz ²² Schlenz ²²
Boarded in ED	ASD predicted boarding OR = 2.5 (1.3-4.7) (P = .01)	Reference	Wharff ²³
Abbreviations: OR = odds ratio, RR = relative	risk.		

study of youth aged 12 months to 17 years, the rates of selfinflicted injury and suicide attempts (leading to emergency room or hospital admission) were found to be 7.6 times higher in youth with ASD as compared to those without.¹⁸ In this study using 2003 Medicaid eligibility and claims data, 1,610 youth with ASD (diagnoses included autism and pervasive developmental disorders) were compared to 92,000 youth without ASD with regard to ED presentations for injuries. In this same sample, the relative risk for injuries inflicted by others, including homicide, was not statistically different for youth with or without ASD.¹⁸

Furthermore, a retrospective chart review of youth with ASD (diagnoses included autism, Asperger, or ASD) under the age of 18 years (mean age 12) who presented to the ED in a tertiary care pediatric center in Canada during a 1-year period (2011) reported that 10% of the visits were for behavior.¹⁴ The most common reasons for presentations of youth with ASD were "other" (fever, headache, cough/ congestion/skin infection, etc), gastrointestinal symptoms, and seizures/altered mental status/paresthesia, all of which were more common than behavioral problems, at 45%, 20%, and 13%, respectively. Infection, injury, and dental reasons were all less common than behavioral presentations.¹⁴

A review of the Nationwide Emergency Department Sample database identified the most common presenting problems to the ED (by age group) for individuals with ASD (autistic disorder, disintegrative disorder, and pervasive developmental disorders) as compared to individuals without ASD.¹⁶ Mood disorders were seen in 5.4% of youth with ASD versus less than 2.4% of those without ASD, and ADHD/conduct disorder/disruptive behavior disorder and disorders of infancy, childhood, and adolescence were seen in 9.5% of youth with ASD versus less than 2.4% in those without ASD.¹⁶ For youth aged 12–15 years with ASD, psychiatric problems including self-injurious behavior and aggression were among the most common reasons to present to an ED. In youth aged 16–18 years with ASD, epilepsy and psychiatric disorders were reported as the most common reasons for ED visits.¹⁶ In another study, the top 3 reasons for ER visits for children both with and without ASD were the same: upper respiratory infections, viral infections, and otitis media.¹⁵

Finally, a retrospective chart review of individuals from an academic pediatric neurology practice with ASD aged 18 months to 18 years who visited the ED identified 36 patients with ASD and a control group of 36 patients matched by race and age.¹³ In this study, those with ASD presented with complaints related to their neurologic condition 36% of the time, while those without ASD presented with these complaints only 5% of the time. Those without ASD were more likely to present with a medical complaint than those with ASD (69% versus 50%, respectively).¹³

There are limited data on the type of service provided for those with ASD in the ED. Cohen-Silver et al¹⁴ reported that the average length of stay in the ED for youth with ASD was 381 minutes (6 hours and 21 minutes), with patients waiting 1 hour on average to be placed in a room and 2 hours on average to be seen by a physician. Another study reported that there were no significant differences in length of stay or cost of medical services for youth with or without ASD.¹³ While no data were provided for youth without ASD, a retrospective chart review of youth with ASD under the age of 18 years (mean age 12) reported that 25% of the visits were repeat visits and that 50% of the repeat visits occurred

It is <u>illegal to post this copyrighted PDF on any web</u> Table 3. Comparison of Diagnostic Frequencies in Children Presenting to the Emergency Department With Versus Without Autism Spectrum Disorder (ASD)

Presenting Problems	With ASD	Comparison Without ASD	Source
Psychiatric/behavioral (frequency %)	13%	1.75%	Kalb ¹⁹
	10%	No comparison	Cohen-Silver ¹⁶
GI problems (frequency %)	20%	Reference	Kalb ¹⁹
Any age	2%	1.60%	Deavenport-Saman ¹⁷
Any age	15%	No comparison	Cohen-Silver ¹⁶
3–5 y (nausea/vomiting, other	4.0%, 3.1%	3.3%, < 2.4%	lannuzzi ¹⁸
6–11 y (nausea/vomiting, abdominal pain)	3.4%, < 2.6%	< 2.6%, 4.4%	lannuzzi ¹⁸
12–15 y (abdominal pain, other GI)	<2.1%, 2.2%	4.8%, < 2.1%	lannuzzi ¹⁸
Seizure/convulsions (frequency %)	9%	<1%	Deavenport-Saman ¹⁷
Any age	13%	<1%	Kalb ¹⁹
Any age	13%	No comparison	Cohen-Silver ¹⁶
3–5 у	5.5%	< 2.4%	lannuzzi ¹⁸
6–19 у	8.4%-8.8%	<2.1%-2.6%	lannuzzi ¹⁸
Neurologic (frequency %)	36%	5%	Casey ¹⁵
Head injury (frequency %)	4%	<1%	Deavenport-Saman ¹⁷
Infection (URI, viral, otitis) (%)	20.9%	18.7%	Deavenport-Saman ¹⁷
Any age	20.0%	No comparison	Cohen-Silver ¹⁶
3–5 y (URI)	13.9%	9.6%	lannuzzi ¹⁸
6–11 y (URI)	10.5%	5.5%	lannuzzi ¹⁸
12–15 y (URI)	6.1%	2.6%	lannuzzi ¹⁸
Urgent vs nonurgent	2.6% More likely nonurgent (P<.01)	Reference	Deavenport-Saman ¹⁷
	CTAS ^a 2: 40%, CTAS 3: 42%, CTAS 4: 25%, CTAS 5: 2%	No comparison	Cohen-Silver ¹⁶
Psychiatric diagnoses			
All psychiatric	13%	2%	Kalb ¹⁹
Psychotic disorder	7.8%	4.4%	Kalb ¹⁹
Anxiety disorder	10.80%	21.80%	Kalb ¹⁹
Mood disorder	36.9%	48.50%	Kalb ¹⁹
	5.40%	< 2.4%	lannuzzi ¹⁸
ADHD/conduct/disruptive behavior/disorders	9.5%	<2.4%	lannuzzi ¹⁸
Externalizing/assaultive	42.1%	22.4%	Kalh ¹⁹
Suicide	2.3%	2 9%	Kalb ¹⁹
Self-injurious	Relative ratio = 7.62 (P = .009)	Reference	McDermott ²⁰

^aCTAS ranges from 1 = high acuity medically unwell to 5 = nonurgent medically stable patient with specific medical concern. Abbreviations: ADHD = attention-deficit/hyperactivity disorder, CTAS = Canadian Triage Acuity Scale, GI = gastrointestinal, URI = upper respiratory infection.

within 1 to 15 days of the initial encounter.¹⁴ Individuals with ASD who visited the ED were more likely to have public insurance (85.9%) than those without ASD (78%)¹⁵ and had 30% higher ED costs.¹⁷

With regard to disposition, Schlenz et al²⁰ reported that preadolescent youth (aged 9-12 years) with ASD were 10.32 times more likely and adolescent youth (aged 13-18 years) were 9.51 times more likely than comparison aged youth without ASD to be admitted to a psychiatric unit. This is consistent with the finding that youth with ASD are more likely to present to the ED with psychiatric or behavioral related symptoms.¹⁶⁻¹⁸ However, individuals with ASD presenting with psychiatric or behavioral issues were also more likely to be medically boarded in the ED or admitted to a medical floor than individuals without ASD, suggesting inpatient psychiatric placement was not available.²⁰ A retrospective cohort study of 461 ED patients requiring psychiatric admission showed that 34.1% were medically boarded and that of these individuals, those with DSM diagnoses of ASD, intellectual disability, or developmental disability were more likely to be boarded than individuals with other diagnoses.²¹ Other studies reported that youth

without ASD were not more likely than those without ASD to be hospitalized on a medical floor, but these addressed all causes for hospital admission rather than specifically those relating to psychiatric or behavioral issues.^{15,20} Youth with ASD who were hospitalized for any reason had a longer average duration of hospitalization (1.46 days longer) than those without ASD.²²

DISCUSSION

To the best of our knowledge, this is the first systematic review of ED service use in children with ASD. Given the high prevalence of ASD in pediatric populations and high costs of ED care, the characteristics, precipitants, types of services, and disposition once these children present to the ED can be helpful in developing care approaches that may prevent or minimize ED use, reduce both emotional and financial burden, and improve outcomes for children.

This review indicates that youth with ASD are more likely than those without ASD to present to the ED and that their visits are more likely to be for behavioral and psychiatric reasons. These data appear in line with our It is illegal to post this copy clinical experience. Studies in adults with autism have also suggested that they have a greater odds of using the ED than adults without autism²³ and may be more likely to present to the ED with psychiatric complaints including episodes of aggression.²⁴ However, the available literature on youth with ASD does not provide insight into the most frequent precipitating behaviors leading to ED visits, address parental decision-making factors leading to ED utilization, identify those at highest risk for presentation, report on experiences of the youth while in the ED, or delineate which services are implemented or available prior to presentation to the ED. In our clinical experience, many youth with autism may be receiving some, but not all available services. For example, an individual may have specialized schooling, psychiatric services, and occupational therapy, but not be connected with the county Board of Developmental Disabilities, which can offer a range of services including in-home early intervention, specialized therapies, respite care, and crisis intervention services. Optimal care for a young individual with autism should involve not only diagnosis, but also a treatment plan that includes comprehensive wrap-around services. Identifying the gaps in service provision through screening and education may help decrease the number of unnecessary emergency room visits for youth with ASD.

A variety of questions remain regarding precipitating factors for ED visits. For example, is assaultive behavior toward family, school staff, or others the primary cause of ED visits or is there another more common precipitating factor? Is there a difference in ED utilization by youth with higher functioning versus lower functioning autism? Are those that present to the ED lacking connection to critical outpatient resources? Are there differences in ED utilization between ASD service rich regions and regions with less services? Is an underlying medical cause (ie, constipation or pain) the precipitant for the behavioral exacerbation? Furthermore, multiple authors acknowledge that parents may have difficulty accessing mental health services for their children.^{25,26} Even if mental health services are available in the community, financial factors, including lack of insurance coverage, can impede access to care for families.²⁷ Average health care costs for youth with ASD were reported in 1 study to be 3 times higher than the costs for children without ASD and children with ASD and psychiatric comorbidities had significantly higher health care costs.⁷ Evidence suggests that without appropriate access to behavioral supports and mental health services, children with ASD and comorbid mental health conditions are at risk for aggression, selfinjurious behavior, and suicidality and therefore more likely to present for emergency care.

In addition, little information exists regarding the experience of individuals with ASD in the ED setting. While 1 study in adults with ASD found that physical restraints were used in 53% of psychiatric/behavioral ED visits,²⁴ none of the studies in youth comment on use of physical or chemical restraints in the ED. Additionally, while length of stay for youth with and without ASD was not found to be different in 1 study,¹³ others found that many ED visits are repeat visits,

often occurring within 1 month of a previous visit.⁴ These findings suggest that discharge planning from the ED and post-ED discharge services are not adequate.

The available literature also provides evidence that there are limited placement options for those with ASD, resulting in suboptimal placement (ie, on medical floors rather than inpatient psychiatric placements or specialized autism units). Chiri and Warfield report that up to 25% of youth with ASD who are hospitalized are admitted for mental health conditions,²⁵ while another study found that engaging in self-injurious or aggressive behavior increased the odds of hospitalization for youth with ASD.²⁸ There is little information regarding treatment, types and efficacy of interventions, and disposition planning for youth with ASD who are admitted to medical floors for psychiatric and/or behavioral problems. In 1 study of children with ASD, the length of stay in the hospital was significantly longer for the ASD cohort with mental health conditions (8.20 days; 95% CI, 7.74-8.68) compared to the non-ASD cohort with chronic medical conditions (6.54 days; 95% CI, 6.11-7.00).²⁹

For those that are discharged from the ED, there is no evidence regarding how ED referrals for outpatient resources influence the outcome for these individuals. Additionally, the available data do not address how ED presentations and subsequent interventions could be used to alter the trajectory or outpatient treatment for youth with ASD. Specifically, if an individual has presented to the ED previously for a similar presentation, which resources were added or improved upon and did these interventions make a difference? Published studies also do not provide any information regarding which services are needed in the community or post-ED discharge to improve outcome for these individuals. Given that resources in the community may not be accessed or may even be completely lacking, how can ED interventions optimize outcomes for youth with ASD? One possibility is to alleviate some of the difficulty in accessing care. For example, communities could develop protocols to ensure that each individual with ASD who presents to the ED is receiving all available services and being linked to appropriate services in the community. Ideally, this process would be done on an outpatient basis prior to any ED visits. However, even with wrap-around services in place, at times parents become overwhelmed and greater support and supervision are needed than the caregivers can provide.

Limitations of this review include that our search criteria were specific to ASD, and while we did include pervasive developmental disorders in our search term, we did not search for articles on general developmental disabilities. Since autism is sometimes classified under this subheading, it is possible articles were missed that may have included individuals with ASD in their analysis. The studies included herein also have major limitations including lack of consistent methodology, less robust study designs, and lack of standardized assessments to identify ASD. Studies also did not differentiate between youth with high versus low functioning ASD, if or how intellectual ability or disability impacted findings, and did not comment on validity of comorbid psychiatric diagnoses or differentiate between sucidal ideation and self-injurious behavior. In addition, the limited number of articles makes generalization of the results difficult; however, given the varied sources of data (from university hospital/tertiary care center studies to national database samples and Medicaid records), there is a greater likelihood of these findings being applicable to a broad population.

Overall, this review found that there is limited published information regarding ED service use by youth with ASD. Future work should include analyses of precipitating events leading to ED visits, what complicating factors can arise in the ED, and how best to provide services that lead to optimal disposition and outcomes. In order to best inform care planning for youth with ASD, more data are needed on how to prevent or minimize ED use and how ED services can be utilized most efficiently for young people who do present in these settings. In addition, there were no interventional studies available to inform care. Interventions for youth in these higher risk categories could help reduce the risk of hospitalization. The stakes are too high for the individuals, family members, and those involved in their care to not better address these areas of concerns. More effort is also needed in the development of appropriate preventive services and treatments to avoid unnecessary ED utilization and hospitalization, reduce medical costs, and improve outcomes for youth with ASD.

Submitted: February 3, 2017; accepted September 18, 2017.

Published online: May 8, 2018.

Potential conflicts of interest: Dr Lytle has received the following research grant funding in the past 3 years: Roche, Forest, Shire, Child Abuse Prevention Fund (Great Lakes Regional Council), and University Hospitals Leadership Council. Dr Sajatovic has received the following research grants within past 3 years: Merck, Alkermes, Janssen, Reuter Foundation, Woodruff Foundation, Reinberger Foundation, National Institutes of Health (NIH), and Centers for Disease Control and Prevention (CDC); has served as a consultant for Bracket, Prophase, Otsuka, Sunovion, Neurocrine, Supernus, and Health Analytics; has received royalties from Springer Press, Johns Hopkins University Press, Oxford Press, and UpToDate; and has conducted CME activities with American Physician's Institute, MCM Education, CMEology, and Potomac Center for Medical Education. Drs Hunt, Moratschek, and Hall-Mennes declare that they have no conflicts of interest.

Funding/support: None.

Previous presentation: Poster presented at the American Academy of Child and Adolescent Psychiatry Annual Meeting; October 26, 2016; New York, New York.

Acknowledgments: We acknowledge the support of the University Hospitals Cleveland Medical Center Psychiatry Leadership Council. We appreciate the valuable assistance of Jennifer Staley, MLIS (University Hospitals Cleveland Medical Center, Cleveland, OH), who assisted in the literature search. Ms Staley has no conflicts of interest to declare.

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Editor's Note: We encourage authors to submit papers for consideration as a part of our Focus on Childhood and Adolescent Mental Health section. Please contact Karen D. Wagner, MD, PhD, at kwagner@psychiatrist.com.