Research Article

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Journal of **Comparative Effectiveness Research**

Healthcare utilization among children with early autism diagnoses, children with other developmental delays and a comparison group

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Aim: To describe healthcare utilization patterns among children with autism (n = 1821), and compare these patterns to children with other developmental delays (DD; n = 12,336) and a population comparison (PC; n = 18,210) cohort. **Materials & methods:** Retrospective study of administrative billing data. **Results:** Children with autism had roughly six-times more annual outpatient visits as PC children and twice as many as children with DD. Children with autism were more likely than PC children to use nearly all services, but comparisons between the autism and DD cohorts were mixed. Children with autism were more likely to have psychiatry/psychology visits, 'other' specialty care visits and psychotropic prescriptions, but less likely to have pediatric specialty care visits, immunizations and some prescriptions. **Conclusion:** Findings reveal opportunities to streamline, coordinate or improve care for young children with autism, particularly for outpatient services, and to give caregivers appropriate anticipatory guidance about what to expect after an autism diagnosis.

Lay abstract: We compared how young children with autism use healthcare services versus children with other developmental delays (DDs) and a population comparison (PC) group. We examined medical billing records of children with private health insurance from across the USA. Children with autism were more likely than PC children to use nearly all healthcare services. Children with autism had about six-times as many annual outpatient visits as PC children and twice as many as children with DD. Children with autism were more likely to use some services and less likely to use other services compared with children with DD. For example, children with autism were more likely to have mental health visits and medications, but less likely to have pediatric specialty care visits or allergy medications. Outpatient visits and other healthcare services may need to be streamlined, coordinated or improved for young children with autism.

First draft submitted: 3 March 2021; Accepted for publication: 13 May 2021; Published online: 28 May 2021

Keywords: autism • developmental delay • health services research • observational research • pediatrics

Providing healthcare for children with autism is often complex, requiring dynamic organization among multiple healthcare providers within complementary disciplines to support social, behavioral, emotional and physical vulnerabilities. Specific needs often include integration of medication management, consultation with subspecialists across physical and mental health disciplines, and coordination of services for frequently co-occurring psychiatric conditions [1,2]. Given the well-recognized constellation of co-occurring conditions among children with autism, it is critical that organizations and providers ensure accessible and responsive longitudinal healthcare experiences and that caregivers can anticipate the extent of care and care coordination that might be needed. The surfacing of significant co-existing conditions over time mirrors an evolution of shifting developmental priorities making care for many patients with autism particularly challenging. Importantly, multiple studies document children with

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autism have greater unmet health needs and lesser quality care than other children with special healthcare needs [3–6]. The ways in which the care for populations with autism trail behind service provision to other communities of patients with developmental delays (DD) need further clarification. Thus, it is essential to understand the health service use patterns among children with autism to create and maintain informed systems of care that are readied and capable fo meeting this population's needs.

Contemporary understanding of the healthcare utilization for children with autism has largely been based on: parent report studies, which are subject to recall bias [7,8]; state-specific population samples, which may have limited generalizability across the nation [9]; or studies focused on specific services, such as emergency department (ED) visits [10–13] or prescription medications [14,15]. To date, relatively few studies have used nationwide US healthcare claims data to study broad patterns of healthcare utilization in children with autism. The most recent multistate study used healthcare claims data from the years 2009–2010 and found that young children with autism were significantly more likely than peers without autism to receive most types of healthcare services, but less likely to receive preventive services [16].

Distinct patterns of healthcare utilization by those with autism have been characterized by age, highlighting how transition planning from young childhood to school age, school age to teenage and teenage to adulthood reflects shifting healthcare needs as well as educational, social and developmental demands. Limited investigation to date supports this multidimensional care coordination as a more pronounced phenomenon for those with autism when compared with other DD populations. Also, emerging evidence demonstrates the specific needs of different age cohorts. Recently, Weiss *et al.* used an administrative dataset to clarify the increased health concerns and service use indicators for teens and young adults with autism compared with peers with DD [17]. This study team concludes there is a need to plan healthcare for young adults with autism in ways different from peers with DD [17]. Similarly, Shea *et al.* tracked Medicaid data to confirm changes in medical service use among adolescents with autism as they age [18].

However, the extent to which the healthcare service needs of children with autism are similar to or distinct from the broader population of children with developmental delays (DD) remains largely unknown, as majority of studies do not include such comparison groups [17]. Moreover, in the last decade, improvements in the reliable identification of autism in young children [19–21] have provided a new opportunity to study healthcare utilization in the first years after an early autism diagnosis. The most recent national estimates of healthcare utilization among children with autism, which were obtained from 2009–2010 data [16], likely are not representative of contemporary utilization patterns given changes in the last decade with regard to: improved diagnostic accuracy for young children; and instatement of mandates requiring private health insurers to cover screening, diagnosis and services for autism [22]. Caregivers often report feeling overwhelmed with navigating the healthcare system to better help their child with autism [23,24]. As such, the child's healthcare utilization patterns after the diagnosis may highlight opportunities to streamline the experience for both the family and the system. The purpose of this study, therefore, is to report updated estimates on healthcare utilization for young children with autism across primary, acute and specialist providers, and to illustrate how children with autism have distinct healthcare utilization compared with children with other DD and a population comparison (PC) cohort using a privately insured sample from across the USA. Such clarity magnifies the vulnerability of those with autism within the larger DD cohort and a need for differential informed care coordination.

Materials & methods

Data source

IBM MarketScan® Commercial Claims and Encounters Databases for the years 2012–2016 were used in this study. De-identified individual-level healthcare claims data for inpatient, outpatient and prescription drug services were used in this analysis.

Study design

A retrospective cohort study design was used to compare the healthcare utilization of children with autism to that of young children with DD and a PC cohort. Children belonging to each cohort were identified using data from 2012 and 2013 (baseline). Healthcare utilization was extracted in 12-month intervals from the years 2014 through 2016 (study period).

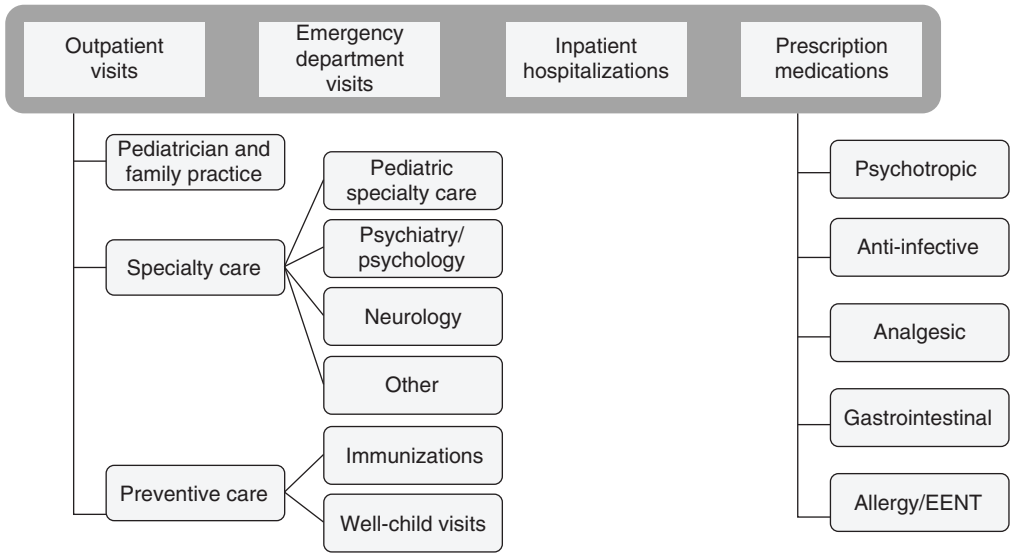

Figure 1. Utilization areas examined. 'Other' specialty care includes visits to: surgery, allergy/immunology, alternative medicine, anesthesiology, dermatology, internal medicine, obstetrics/gynecology, ophthalmology, rehabilitation, surgery, therapy, urgent care and urology providers that were not specifically designated as pediatric. EENT: Eye, ear, nose and throat.

Sample selection

This study included children who were under 5 years of age during the baseline period of 1 January 2012–31 December 2013, and were continuously insured during the study period of 1 January 2014–31 December 2016. The autism cohort (n = 1720) was defined by the presence of at least two outpatient visits or one inpatient hospitalization with an autism diagnosis during the baseline period (years 2012–2013). Autism diagnoses were defined by International Classification of Diseases, Ninth Revision, Clinical Modification codes for autism (299.0), Asperger disorder (299.8) or pervasive developmental disorder not otherwise specified (299.9). As we examined healthcare utilization during 2014–2016, this study focused on young children with existing autism diagnoses as opposed to those undergoing the process of obtaining a diagnosis.

The DD cohort (n = 4765) was defined as children with at least one medical encounter during the baseline period with a diagnostic code for DD (783.4, 783.42, 315.5x, 315.8x and 315.9x). Children were excluded from the DD cohort if they had an autism diagnosis at any time during baseline (2012–2013) or the study period (2014–2016).

We also selected a PC sample of the remaining children who did not have an autism or DD diagnosis at any time during baseline or the study period. The PC sample was group frequency matched to the autism sample by age and sex at a 3:1 ratio of PC children (n = 5160) to children with autism.

Variables

The primary independent variable for this study was cohort membership. The primary dependent variables were dichotomous indicators of the presence of at least one outpatient visit, inpatient hospitalization, ED visit and prescription medication per year. Figure 1 summarizes these four main utilization areas as well as secondary outcomes we analyzed. The following covariates were included due to their potential association with healthcare utilization: sex, age, presence of any psychiatric condition (e.g., anxiety and mood disorders) and rural residence as defined by dwelling in a nonmetropolitan statistical area. Age was analyzed as a categorical variable in 2-year intervals, except ages 1–4 were collapsed into a single category due to low frequencies of children in this age range.

Statistical analysis

Demographic characteristics were summarized descriptively. We used repeated measures logistic regression models to compare cohorts on the odds of least one medical encounter for each service type per year. Additionally, for each service type, we conducted cross-sectional analyses using negative binomial regression to compare the cohorts on the annual number of encounters among children with at least one encounter. We performed all statistical analyses using SAS statistical software, version 9.4.

Table 1. Demographic and clinical characteristics of privately insured young children with ASD, other developmental disorders and PC children.

Demographic and clinical characteristics	ASD	DD	PC
Children in study, n	1720	4765	5160
Males, %	81.5	62.5	81.5
Age of diagnosis, mean ± SD	3.21 ± 0.78	2.29 ± 1.01	
Years of age in 2014, mean ± SD	4.94 ± 0.91	4.22 ± 1.02	4.94 ± 0.91
Rural,† %	6.9	9.2	12.4
US region of residence, %			
– South	36.9	36.9	42.0
– Northeast	28.0	32.8	19.1
– West	19.1	14.6	17.8
– North central	16.0	15.8	21.1
Insurance plan, %			
– PPO	59.8	68.1	59.5
– HMO	12.6	8.7	10.9
– Consumer-driven health plan	11.9	10.4	14.7
– High deductible health plan	7.7	5.9	7.9
– POS	6.8	6.0	5.9
– Comprehensive, EPO, or capitated POS	1.3	0.8	0.8
Psychiatric condition, %			
– ADHD	36.7	17.8	
– Adjustment disorder	5.0	5.4	1.9
– Anxiety	18.7	9.4	2.5
– Mood or impulse disorder	4.7	2.3	0.4

†Rural residence was defined as living in a nonmetropolitan statistical area.
ADHD: Attention deficit hyperactivity disorder; ASD: Autism spectrum disorder; DD: Other developmental disorder; EPO: Exclusive provider organization; HMO: Health maintenance organization; PC: Population comparison; POS: Point-of-service; PPO: Preferred provider organization; SD: Standard deviation.

Results

We identified 1720 and 4765 young children with autism and DD, respectively, and 5160 PC children who were continuously insured during the study period. Relative to the DD cohort, a higher percentage of children with autism was male (Table 1). Fewer children in the autism and DD cohorts lived in rural areas than children in the PC cohort (Table 1). The Southern USA and preferred provider organization were the most common region of residence and insurance plan type, respectively, which is consistent with the overall distributions of these variables in the MarketScan databases. Psychiatric conditions were more common among children with autism or DD than among PC children. Thus, where appropriate, we controlled for sex, rural residence and any psychiatric conditions.

Odds of at least one visit/prescription

Table 2 provides the odds ratios from the repeated measures logistic regression models comparing children with autism to each of the other two cohorts across age categories while controlling for sex, any psychiatric condition and rural residence. Children with autism had significantly greater odds of at least one outpatient specialty care visit than children with DD (1.3–1.8x greater odds) and PC children (4.0–6.2x greater odds) across all age categories (Table 2). With regard to specific types of outpatient specialty care visits, children with autism had greater odds of at least one psychiatry/psychology visit than children with DD (2.3–3.4x greater odds) and PC children (13.7–31.1x greater odds). Children with autism had significantly lower odds than children with DD, but significantly greater odds than PC children, of having an outpatient pediatric specialty care visit (e.g., pediatric oncology and pediatric cardiology). Children with autism also had significantly greater odds of a neurology visit and an 'other' outpatient specialty visit than PC children (14.7–32.1 and 3–4x greater odds, respectively). PC children and children with autism had similar odds of preventive service utilization, but during age 1–4 years, children with autism had significantly lower odds of having an immunization or well-child visit than children with DD.

Table 2. OR from the logistic regression models comparing children with ASD to each of the other two cohorts across age categories.

Service type	ASD vs DD OR (95% CI)			ASD vs PC OR (95% CI)		
	1–4 Years	5–6 Years	7–8 Years	1–4 Years	5–6 Years	7–8 Years
Outpatient visits						
– Pediatrician & family practice	1.2 (0.9, 1.7)	0.8 (0.6, 0.9)‡	0.7 (0.5, 0.9)	1.6 (1.1, 2.3)‡	1.0 (0.9, 1.3)	1.0 (0.7, 1.3)
– Specialty care	1.8 (1.4, 2.2)‡	1.5 (1.3, 1.7)†	1.3 (1.1, 1.6)†	6.2 (5.0, 7.8)†	4.6 (4.0, 5.2)†	4.0 (3.2, 4.9)†
– Pediatric specialty care	0.7 (0.6, 0.9)‡	0.6 (0.6, 0.7)†	0.8 (0.6, 0.9)†	3.2 (2.5, 4.1)†	2.7 (2.3, 3.2)†	3.2 (2.6, 4.1)†
– Psychiatry/psychology	3.4 (2.7, 4.4)†	3.2 (2.7, 3.7)†	2.3 (1.8, 2.9)†	31.1 (16.9, 57.1)†	22.9 (17.4, 30.2)†	13.7 (10, 18.9)†
– Neurology	1.3 (1.1, 1.7)	1.2 (1.0, 1.4)	1.0 (0.7, 1.3)	32.1 (16.6, 62)†	25.3 (17.4, 36.8)†	14.7 (9.7, 22.4)†
– Other	1.5 (1.2, 1.8)†	1.3 (1.1, 1.4)†	1.0 (0.8, 1.2)	4.4 (3.6, 5.4)†	3.4 (3.0, 3.8)†	2.6 (2.1, 3.1)†
– Preventive services	0.7 (0.5, 0.8)†	0.8 (0.7, 1.0)	0.8 (0.7, 1.0)	0.8 (0.7, 1.0)	0.9 (0.8, 1.1)	1.0 (0.8, 1.2)
– Immunizations	0.7 (0.6, 0.8)†	0.8 (0.7, 0.8)†	0.8 (0.7, 1.0)	0.8 (0.7, 1.0)	0.9 (0.8, 1.0)	1.1 (0.9, 1.3)
– Well-child visit	0.7 (0.6, 0.9)†	0.9 (0.8, 1.0)	0.9 (0.8, 1.1)	0.9 (0.7, 1.0)	1.0 (0.9, 1.1)	1.0 (0.8, 1.2)
Inpatient hospitalizations	0.8 (0.5, 1.2)	0.7 (0.6, 0.9)	0.5 (0.3, 0.8)‡	5.1 (2.8, 9.1)†	5.0 (3.5, 7.2)†	4.3 (2.2, 8.2)†
ED visits	1.1 (0.9, 1.4)	1.0 (0.9, 1.1)	0.9 (0.7, 1.2)	1.7 (1.3, 2.2)†	1.7 (1.5, 2.0)†	1.4 (1.1, 1.8)‡
Prescription medications	0.9 (0.8, 1.1)	0.8 (0.7, 0.9)‡	0.8 (0.7, 1.0)	1.6 (1.3, 1.9)†	1.2 (1.1, 1.4)†	1.3 (1.1, 1.5)‡
– Psychotropic agents	1.2 (0.9, 1.6)	1.8 (1.5, 2.1)†	1.7 (1.3, 2.1)†	4.4 (2.7, 6.9)†	10.5 (8.3, 13.4)†	19.0 (13.8, 26.0)†
– Anti-infective agents	0.9 (0.8, 1.1)	0.8 (0.7, 0.9)†	0.7 (0.6, 0.9)‡	1.4 (1.2, 1.7)†	1.1 (0.9, 1.2)	0.9 (0.8, 1.1)
– Analgesic agents	0.7 (0.5, 1.1)	0.6 (0.5, 0.8)†	0.8 (0.5, 1.2)	1.6 (1.0, 2.7)	1.3 (1.0, 1.8)	1.8 (1.2, 2.7)‡
– Gastrointestinal agents	1.0 (0.8, 1.3)	1.0 (0.8, 1.1)	0.9 (0.7, 1.2)	3.4 (2.5, 4.7)†	2.0 (1.6, 2.3)†	2.0 (1.5, 2.7)†
– Allergy/EENT	0.9 (0.8, 1.1)	0.8 (0.7, 0.9)†	0.7 (0.6, 0.9)‡	1.6 (1.3, 2.0)†	1.2 (1.1, 1.4)†	1.2 (1.0, 1.4)

†$p < 0.001$;
‡$p < 0.01$.
ASD: Autism spectrum disorder; DD: Other developmental disorder; ED: Emergency department; EENT: Eye, ear, nose and throat; OR: Odds ratio; PC: Population comparison.

Across age categories, children with autism had significantly greater odds than PC children, but not children with DD, of having at least one inpatient hospitalization, ED visit and any prescription medication. With regard to specific prescription types, children with autism aged 5–6 and 7–8 years had significantly greater odds of having at least one psychotropic prescription medication (1.7–1.8x greater odds), but lower odds of at least one anti-infective or allergy/eye, ear, nose and throat prescription medication, than children with DD. Children with autism had greater odds than PC children of having a gastrointestinal prescription (2–3x greater odds) or a psychotropic medication (4–19x greater odds).

Annual number of visits/prescriptions

Table 3 depicts the results of the cross-sectional analysis to compare the cohorts on the number of encounters, among children with at least one corresponding encounter type. Children with autism averaged 36.9 outpatient visits annually, compared with 23.2 for children with DD and 6.5 for the PC cohort (Table 3; $p < 0.001$). This includes pediatric/family practice care, specialist care and preventive care. When examined by specific outpatient visit types, children with autism had significantly more specialty care visits (average number of annual visits autism: 37.2; DD: 18.4; PC: 3.0), psychiatry/psychology visits (average number of annual visits autism: 19.9; DD: 5.4; PC: 2.7) and 'other' specialty care visits (average number of annual visits autism: 32.7; DD: 16.5; PC: 2.7) than either comparison cohort. On average, children with autism had significantly fewer visits for pediatricians and family practice, pediatric specialty care, and neurology than children with DD, but significantly more than PC children. Children with autism had fewer annual preventive service visits (1.9) than children with DD (3.1) or PC children (2.7) ($p < 0.001$).

Among children with at least one hospitalization, children with autism spent over twice as many days in the hospital than PC children on average ($p < 0.001$) but did not differ significantly from children with DD (Table 2). No significant differences were found between cohorts on the average annual number of ED visits.

Children with autism had significantly more prescriptions than PC children for all prescription types examined, except anti-infective prescriptions (Table 3). However, children with autism had significantly fewer prescriptions

Table 3. Adjusted† annual number of encounters among children with at least one corresponding encounter.

Encounter type	ASD		DD		PC	
	Mean (95% CI)	N	Mean (95% CI)	N	Mean (95% CI)	N
Outpatient visits	36.9 (35.3, 38.7)	1700	23.2 (22.6, 23.9)‡	4748	6.5 (6.4, 6.7)‡	5128
Pediatrician & family practice	5.5 (5.3, 5.7)	1601	7.4 (7.2, 7.5)‡	4619	4.6 (4.5, 4.7)‡	4948
Specialty care	37.2 (34.9, 39.7)	1463	18.4 (17.7, 19.1)‡	4168	3.0 (2.9, 3.1)‡	3541
– Pediatric specialty care	2.3 (2.1, 2.5)	436	3.1 (2.9, 3.2)‡	1909	1.4 (1.3, 1.5)‡	786
– Psychiatry/psychology	19.9 (17.5, 22.6)	492	5.4 (4.9, 6.1)‡	734	2.7 (2.1, 3.5)‡	123
– Neurology	1.6 (1.4, 1.8)	285	2.1 (2.0, 2.3)‡	852	1.1 (0.8, 1.4)§	73
– Other specialty care	32.7 (30.6, 35.1)	1325	16.5 (15.8, 17.1)‡	3970	2.7 (2.6, 2.9)‡	3324
Preventive services	1.9 (1.8–2.0)	1440	3.1 (3.1–3.2)‡	4577	2.7 (2.6–2.7)‡	4815
– Immunizations	0.8 (0.7, 0.8)	959	0.9 (0.9, 0.9)‡	3510	0.8 (0.8, 0.8)	3337
– Well-child visit	1.2 (1.1, 1.2)	1201	1.6 (1.6, 1.7)‡	4240	1.4 (1.4, 1.5)‡	4366
Inpatient hospital days	3.7 (2.9, 4.7)	103	5.2 (4.8, 5.8)§	588	1.3 (1.0, 1.7)‡	109
ED visits	0.8 (0.7, 0.9)	426	0.9 (0.8, 0.9)	1638	0.7 (0.7, 0.7)	1207
Prescription medications	4.5 (4.2, 4.7)	1279	5.9 (5.7, 6.1)‡	4268	2.8 (2.7, 2.9)‡	4374
– Psychotropic agents	5.2 (4.6, 5.8)	383	5.3 (4.9, 5.7)	802	1.5 (1.3, 1.9)‡	178
– Anti-infective agents	2.1 (2.0, 2.2)	1114	3.0 (2.9, 3.1)‡	4002	2.0 (1.9, 2.0)	4077
– Analgesic agents	0.8 (0.7, 1.0)	123	0.8 (0.8, 0.9)	663	0.6 (0.6, 0.7)§	391
– Gastrointestinal agents	2.4 (2.1, 2.7)	284	3.1 (2.9, 3.3)‡	1154	0.9 (0.8, 0.9)‡	723
– Allergy/EENT	1.5 (1.4, 1.6)	651	1.9 (1.9, 2.0)‡	2735	1.2 (1.2, 1.3)‡	2356

†Obtained from negative binomial regression models controlling for sex, any psychiatric condition and rural residence.
‡Significantly different from children with ASD, $p < 0.001$.
§Significantly different from children with ASD, $p < 0.01$.
ASD: Autism spectrum disorder; DD: Other developmental disorder; ED: Emergency department; EENT: Eye, ear, nose and throat; PC: Population comparison.

than children with DD for all prescription types examined, except for the number of psychotropic and analgesic prescriptions, which did not differ between these groups.

Discussion

This paper offers a unique contribution to the literature by providing more updated estimates on healthcare utilization patterns among young children with autism than what is currently available [16]. Given advances in diagnostic stability in young children and mandates requiring private insurers to cover autism-related care, utilization estimates from over a decade ago are unlikely to represent contemporary utilization patterns. Our study of healthcare utilization by young children with early autism diagnoses advances our understanding of how, when and with whom services are sought. This is an important first step toward identifying policy recommendations for improving access, building capacity among providers for coordinating and streamlining care, providing anticipatory guidance to parents when young children are diagnosed with autism, and supporting unforeseen or critical expenditures for ongoing heath. This is the first study, to our knowledge, to longitudinally examine national patterns of healthcare utilization in privately insured children with autism who are under 9 years of age. Additionally, our paper is one of few studies to compare children with autism to another clinical population (DD cohort); this DD comparison cohort allows for better understanding the different needs of children with autism from children with other DDs.

Overall, our findings indicated that young children with autism experience nearly a sixfold increase in annual outpatient care relative to PC children, and nearly a twofold increase relative to children with DDs. Roughly speaking, this means families of PC children have an outpatient appointment about once every 2 months, families with a child with DD about twice a month and families of children with autism are averaging one every 10 days. This finding alone – even without considering ED visits, inpatient hospitalizations and prescriptions – suggests a potentially tremendous burden on families of children with autism or DD with regard to logistics, school and work interruptions, and copayments.

Children with autism have higher rates of co-occurring physical health conditions (e.g., epilepsy, sleep disturbances, etc.) [25,26] that require specialized care. Additionally, they meet with a variety of specialists like psychologists, outpatient therapists and rehabilitation professionals for outpatient intervention to address social skills, communication and daily functioning [9]. While a more nuanced examination of the specific type of outpatient specialty

care that may contribute most to the observed pattern of utilization and expenditures was beyond the scope of the present study, this should be considered in future work. This could be a key area to find opportunities for streamlining services for both families and providers.

Contrary to prior findings [16], children with autism in our study did not differ from PC children in the odds of receiving preventive services such as vaccinations and well-child visits. However, children with DD (on average) had one more preventive visit than their autistic peers or PC peers. This finding highlights the importance of studying utilization and healthcare needs of children with autism as distinct from the larger population of children with DD.

Children with autism were significantly more likely than PC peers, but not those with DD, to have an inpatient hospitalization, ED visit or any prescription medication across age categories. The reasons for increased likelihood of inpatient hospitalizations and ED visits among children with autism and DD were beyond the scope of the present study. However, literature points to likely factors such as less access to a primary care medical home that provides coordinated, family-centered care [27,28]. Additionally, children with autism may be more likely to visit the ED for conditions that are nonemergent [29,30] or may have been prevented with quality primary care (i.e., are ambulatory care sensitive) [31]. With regard to prescriptions, co-occurring physical and mental health conditions often increase in prevalence as children age [32] and more medications are safe and available for use to treat such conditions [33]. While our investigation is limited to a study of early years, other studies have found increased likelihood of inpatient hospitalizations [34], ED visits [35] and prescription medications [36] among adolescents and adults with autism relative to PC peers. Our results suggest that these trends begin in early childhood.

Limitations

Our data do not include services outside of private insurance billing, including those offered through school districts. Additionally, the outcomes examined in this study represent only healthcare services that children actually received and would not capture unmet healthcare needs. We were also unable to examine the quality of the services received by each cohort. We studied a population with private medical insurance rather than primary Medicaid, perhaps limiting the generalizability of our findings. Recognizing health disparities exist within many populations, we were unable to control for variables not contained within this administrative billing data, including annual household income, parental level of education, race and ethnicity. Early diagnoses may also suggest more prominent autism characteristics [37,38], making it possible that the children included in the autism cohort may not be representative of the entire autism spectrum; that is, those with fewer autism characteristics may have been less likely to receive an early diagnoses, and thus would have been excluded from this work. Of note, we intentionally chose to study utilization following identification of autism, excluding visits and costs related to receiving a diagnosis.

Conclusion

There is a nationally recognized need for better service models to improve consistency of care and ultimately health outcomes for individuals with autism [39]. Our study can inform such initiatives by providing a comparison of private insurance-based healthcare utilization of young children with autism to that of children with other DDs and a PC cohort using a large sample from across the USA. Given the well-recognized constellation of co-occurring physical and mental health conditions among children with autism, it behooves communities and insurance providers to ensure feasible, accessible and responsive longitudinal healthcare experiences. Results of this study indicate that children with autism utilize outpatient care at a rate that so greatly exceeds their DD and PC counterparts that it likely presents a significant logistical and financial burden on families almost immediately after diagnosis, and that looking specifically at the distinct needs of children with autism may uncover opportunities to streamline, coordinate or improve care and outcomes.

Summary points

- In the last decade, improvements in the identification of autism in young children have provided a new opportunity to study healthcare utilization in the first years after an autism diagnosis.
- We conducted a retrospective cohort study to compare patterns of healthcare utilization of privately insured children with autism to those children with developmental delays (DDs) and a population comparison (PC) cohort.
- Across age categories, children with autism had significantly greater odds than PC children of having most visit types and prescriptions examined but had similar odds of preventive service utilization.
- Children with autism had greater odds than children with DD of having a specialty care visit, psychiatry/psychology visit, 'other' specialty care visit or prescription for psychotropic medication, but lower odds

of having a pediatric specialty care visit, immunization, anti-infective prescription, and allergy/eye, ear, nose and throat prescription.
- On average, children with autism have approximately one outpatient visit every 10 days, while children with DD have approximately two outpatient visits per month and PC children have approximately one outpatient visit every other month.
- Children with autism tended to have significantly more visits and prescriptions annually than PC children across most types of healthcare services examined.
- Children with autism had more annual outpatient visits of any type, specialty care visits, psychiatry/psychology and 'other' specialty care visits than children with DD, but significantly fewer visits and prescriptions across most other types of healthcare services examined.
- Findings indicate there may be a considerable burden from frequent outpatient visits among families of children with autism with regard to logistics, school and work interruptions, and copayments.
- Examining the needs of children with autism as distinct from children with DD may uncover opportunities to streamline, coordinate or improve care and outcomes.

Financial & competing interests disclosure

The authors have no relevant affiliations or financial involvement with any organization or entity with a financial interest in or financial conflict with the subject matter or materials discussed in the manuscript. This includes employment, consultancies, honoraria, stock ownership or options, expert testimony, grants or patents received or pending, or royalties.

No writing assistance was utilized in the production of this manuscript.

Ethical conduct of research

All applicable institutional and governmental regulations concerning the ethical use of human volunteers were followed during the course of this research. Institutional review board exemption was obtained from Ohio State University as data were de-identified.

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