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ORIGINAL PAPER

The Association of the Medicaid 1915(c) Home and Community-Based Services Waivers with Emergency Department Utilization among Youth with Autism Spectrum Disorder

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Abstract

Using the 2008–2013 Medicaid Analytic eXtract files, this retrospective cohort study was to evaluate the effect of Medicaid home and community-based services (HCBS) waiver programs on emergency department (ED) utilizations among youth with autism spectrum disorder (ASD). Our study showed that the annual ED utilization rates were 13.5% and 18.8% for individuals on autism specific and intellectual and developmental disabilities (IDD) waivers respectively, vs. 28.5% for those without a waiver. Multivariable logistic regression showed that, compared to no waiver, autism specific waivers (adjusted odds ratio: 0.62; 95% Confidence Interval: [0.58–0.66]) and IDD waivers (0.65; [0.64–0.66]) were strongly associated with reduced ED. These findings suggest that HCBS waivers are effective in reducing the incidence of ED visits among youth with ASD.

Keywords Autism spectrum disorder · Medicaid · Home and community-based services waiver · Emergency departments

Introduction

Autism spectrum disorder (ASD) is a complex developmental disorder characterized by restricted and repetitive behavior and delayed social interaction and communication (American Psychiatric Association, 2013). As prevalence rates have continued to increase over the past decade (Maenner et al., 2020), so too has our knowledge about treating children with ASD. Symptoms typically appear within the first two years of life and should be followed quickly with testing, diagnosis and a treatment plan. An abundance of evidence supports the premise that participating in frequent intensive evidence-based behavioral treatment, beginning at a young age, improves children's development (Estes et al., 2015; Landa, 2018; Pickles et al. 2016; Zwaigenbaum et al., 2015) and enhances their cognitive and adaptive functioning (Lovaas, 1987; Nahmias et al., 2019; Politte et al., 2015; Reichow, 2012; Smith et al., 2019; Warren et al., 2011).

The costs associated with intensive treatment, however, are prohibitive for most families. In response to the financial burden imposed on families of children with ASD, all 50 states and the District of Columbia (DC) now mandate that certain insurance companies cover the costs of ASD services (Callaghan & Sylvester, 2019). While mandates can be helpful, many include restrictions (Choi et al., 2020) and generally do not cover long term support services (Eiken et al. 2014).

Medicaid serves a large number of children with ASD but does not adequately cover important and costly services for these children, leaving critical services unobtainable for those on Medicaid as well. Another approach some states have been using since the early 1980s is to offer a Medicaid 1915(c) home and community-based services (HCBS) waiver. HCBS waivers are used to reduce the number of individuals receiving long-term healthcare in institutions or other restrictive settings by providing

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services in individuals' homes and communities (Omnibus Budget Reconciliation Act, 1981). Although waivers must be cost neutral (expenses cannot exceed the cost of institutional care), states have the flexibility to define populations by age, geographic location, and medical condition, and can limit the number of people receiving services, add services not listed in their state plans, and disregard income and resource rules customarily used to determine Medicaid eligibility (Kitchener et al., 2003).

Children with ASD may be able to enroll in an ASD waiver or in an intellectual and developmental disabilities (IDD) waiver that includes ASD in its target population (Velott et al. 2015). Briefly, ASD waivers are newer (post 2000), only available in a few states, typically have more stringent age limits, enroll fewer children, and are more likely to limit children to three years on the waiver. In contrast, IDD waivers are generally older (1980s-1990s), available in many states, allow larger numbers to enroll, are much more likely to allow enrollment through age 18 and do not limit the number of years children may remain on the waiver.

Waiver demand far exceeds supply as evidenced by excessively long waiting lists. In 2017, over 471,000 individuals with IDD were on a waiting list. For people with IDD, the average wait time to secure a slot was five and a half years (Musumeci et al. 2019). State waiting list practices differ across states with some prioritizing by the application date (first come, first served) or by people moving out of – or at risk for returning to – institutional care. Assessment tools are used in some states to gauge applicants' functional skills and level of need, while still other states do not maintain a list (Cooper, 2017; MACPAC 2020; Musumeci et al. 2020).

The body of research for waiver participation and outcomes for children with ASD is small but growing. Participation in an HCBS waiver is expected to afford youth with ASD access to medical care on a more regular basis, such as routine access to outpatient clinics, including regularly scheduled visits to primary care providers (PCPs), psychiatrists specialized in ASD and other specialists. In addition, ASD and IDD waivers expand traditional Medicaid coverage by offering participants evidence-based treatments such as Applied Behavioral Analysis (Merryman et al., 2015; Miller et al., 2016) and care services including case management, caregiver support and training, respite care and personal care services. Compared with children that have ASD and are not receiving services, researchers have consistently found that children enrolled in an ASD waiver experienced improvement in their independent living skills while their parents reported improvements in their family's quality of life (Eskow et al., 2011; Eskow, Chasson, & Summers, 2015, 2019; Miller et al., 2016).

Dependable access to healthcare is essential for children with ASD as children may experience behavioral inflexibility, self-injurious behaviors, and sensory hypo- and hypersensitivities (Samson et al., 2014). In addition, close to 95% of children with ASD have at least one comorbid psychiatric, neurologic, or physical condition (Soke et al., 2018). Among children with developmental disabilities, including ASD, ED utilization was found to be 2.5 times higher than it was for those without a developmental disability (Wharff et al., 2011). Because higher rates of ED visits may indicate that children are having trouble accessing care, it is important to look at ED rates in relation to service availability and access. The shortage of community-based outpatient care for children and adolescents with ASD has been well documented, and it has been suggested that if children and adolescents received adequate non-urgent care services, they might not feel the need to present to the ED (Green et al., 2001; Krauss et al. 2003; Leichtman et al. 2001). The services offered by HCBS waivers may play an important role in helping families manage their children's core symptoms as well as their comorbid physical and mental health illnesses, potentially reducing triggers for acute adverse events that can lead to costly ED visits. Given the positive outcomes found to be associated with waiver enrollment, we hypothesize that enrollment in an ASD waiver will be associated with fewer visits to the ED. To investigate our hypothesis, we determine whether the annual odds of ED visits differ for youth with ASD depending upon whether they are enrolled in an ASD waiver, an IDD waiver, any other waiver, or are not enrolled in a waiver.

Methods

Data Source and Study Cohort

In this retrospective cohort study, we used Medicaid Analytic eXtract (MAX) files to analyze the incidence rates of ED visits in youth with ASD from 2008 through 2013. MAX administrative data consist of person-level data files containing information about Medicaid eligibility; service utilization; payments for inpatient, outpatient, long-term care, and prescription drug service use; and demographics such as age, sex, geographic location, and reason for Medicaid eligibility. Claims for individuals are identified and automatically linked over time and across different types of care by a unique combination of a Medicaid Statistical Information System Identifier (MSIS ID, which is unique within each state) and state ID. The claims contain medical diagnoses coded using the International Classification of Diseases, Ninth Revision (ICD-9). Medical procedures and other services are coded by Current Procedural Terminology, 4th edition (CPT-4) or by the Healthcare Common Procedure Coding System (HCPCS).

We included youth with ASD age 21 and younger from all 50 states plus DC in our study cohort. Individuals with at least 2 outpatient visits or 1 inpatient admission/long-term care claim with a diagnosis of ASD (ICD-9 codes 299.xx) were considered to have ASD (Burke et al., 2014). The number of ASD and IDD waivers available in any one year can change as state administrators make decisions about adding, terminating or amending waivers in their state. Although 54 ASD and IDD waivers that served children with ASD were available in 2020, during our study period the number ranged from 38 in 2008 to 43 in 2013. This study was approved by the Institutional Review Board of the Pennsylvania State University College of Medicine.

Measures

Visits to the ED were identified by CPT-4 codes 99281, 99282, 99283, 99284, 99285 or HCPCS code Z7502. A count variable was then defined for each full calendar year to indicate how many ED visits a subject had during that year. We categorized youth as being enrolled in an HCBS waiver based on the annual waiver type variable. We grouped youth into four categories: ASD waivers (waivers exclusively for those with ASD), IDD waivers (waivers for individuals with intellectual disabilities, developmental disabilities, and autism), other waivers (waivers targeting mental illness, serious emotional disturbance, aged or disabled, brain injury, HIV/AIDS, medically fragile, and technology dependent), and no waiver (individuals not enrolled in a waiver during the year). Individuals with a missing waiver type were excluded from the study sample. We grouped the Medicaid eligibility code into 3 categories: blind/disabled; child poverty; and foster care. For our analyses, we also included age, both at cohort entry and during current year of observation (grouped by age bracket: under 6, 6–8, 9–11, 12–14, 15–17, and 18–21), sex, race/ethnic group, calendar year at cohort entry and state.

Statistical Analysis

First, we conducted descriptive analyses to examine the average annual incidence of ED visits during the study period stratified by waiver status and demographics. Next, we performed a multivariable Poisson regression analysis to evaluate the impact of waiver participation on the annual incidence rate of ED visits. Specifically, we used the generalized estimating equation (GEE) method with a log link function to estimate the multivariable Poisson regression model. We assumed an independent working correlation structure and used empirical robust estimators of standard errors in the GEE analysis to account for the correlations of repeated measures within the subjects. The number of ED visits during each calendar year was the outcome variable in the model. The main explanatory variable of interest was HCBS waiver status, which may vary over time. Other covariates included in the regression model were sex, age group at current year, race and ethnic group, the state in which the subject was enrolled in Medicaid during the year, age group at cohort entry, and calendar year at cohort entry. In the regression analysis, we calculated the adjusted incidence rate ratios and 95% confidence intervals. We performed all analyses using SAS version 9.4 software (SAS Institute, Cary, NC). All tests were two-sided, with p-values less than 0.05 considered statistically significant.

Results

Cohort Characteristics

Our cohort consisted of 574,337 subjects with ASD (Table 1) from 2008 to 2013. Most subjects (77.3%) were first observed in the first year of the study period (2008). The average age when subjects entered the cohort was 8.4 years (sd: 5.6), and the median follow-up time was five years. Subjects were predominantly male (77.9%) and the plurality were White (49.8%). There were 2,663,460 annual observations from our study cohort. Averaging over the six-year study period, the annual rate of enrollment in an

Table 1 Characteristics of children and adolescents with autism spectrum disorder

Characteristics	
Total sample size	574,337
Age at cohort entry (mean, sd)	8.4 (5.6)
Sex, n (%)	
Male	447,600 (77.9%)
Female	126,737 (22.1%)
Race/Ethnic Group, n (%)	
White	286,022 (49.8%)
Black/African American	92,160 (16.1%)
American Indian/Alaskan Native	5,060 (0.9%)
Asian / Native Hawaiian or Pacific Islander	11,360 (2.0%)
Hispanic/Latino	47,896 (8.3%)
Hispanic/Latino plus one or more races	22,588 (3.9%)
More than one race	7,379 (1.3%)
Unknown	101,872 (17.7%)
Year, n (%)	
2008	444,050 (77.3%)
2009	47,588 (8.3%)
2010	33,266 (5.8%)
2011	29,164 (5.1%)
2012	14,053 (2.5%)
2013	6,216 (1.1%)

HCBS waiver was 13.0%; 0.4% in an ASD waiver; 11.2% in an IDD waiver; and 1.4% in any other waiver (Table 2). Enrollment rates for different waiver types varied by age and race/ethnicity but appeared to be similar between males and females. Annual enrollment rates in any waiver type for those under age 6 were below 4%. The IDD waiver enrollment rate increased considerably with age, whereas ASD waiver enrollment increased only slightly with age. The Asian/Native Hawaiian/Pacific Islander group had the highest enrollment rates on both the ASD waiver (0.7%) and the IDD waiver (28.3%), while the Hispanic/Latino plus one or more races group had the lowest rates with 0.1% and 7.1% for the ASD and IDD waiver, respectively.

Descriptive Analysis

The average annual incidence of ED visits between 2008 and 2013 was 0.52 (95% confidence interval [CI]: [0.51–0.53]. By waiver status, the incidence of ED visits was the lowest in a year on an ASD waiver (0.21 [0.19–0.23]), followed by an IDD waiver (0.36 [0.35–0.36]), other waiver types (0.51 [0.49–0.53]), and not on a waiver (0.54 [0.54–0.54]). This pattern was consistently observed across most subgroups when the cohort was stratified by sex, age or race/ethnicity (Fig. 1). In particular, the incidence of ED visits in a year on an ASD waiver was about 50% lower than that without any waiver in most of the subgroups. The IDD waiver was also associated with lower incidence of ED visits compared to other waivers and no waiver. In addition, we examined the association of ED visits with waiver type by Medicaid eligibility (Fig. 1). Of children enrolled as blind/disabled or foster care, ASD waiver enrollees had the lowest incidence of ED visits among the waiver classifications. However, for subjects covered by Medicaid due to poverty, those with IDD waivers had the lowest incidence of ED visits.

Multivariable Regression Analysis

The results from multivariable Poisson regression analysis aligned with the findings from the descriptive analysis. HCBS waivers were consistently associated with a lower incidence rate of ED visits (Table 3). The annual incidence rate of ED visits was 40% lower with the ASD waiver (adjusted incidence rate ratio [aIRR] 0.58, 95%CI: [0.54–0.63]) and 30% lower with the IDD waiver (0.70 [0.68–0.71]), compared to not having a waiver. The effect of the ASD waiver was also significantly stronger than the IDD waiver (0.84 [0.77–0.90]), all with p-values < 0.0001. On the other hand, no significant effect was found for the other waiver types relative to no waiver.

The incidence rate of ED visits was not linearly associated with age. The incidence was higher for a child under 6 years old (reference group) and decreased significantly at ages 6–8 (aIRR: 0.66 [0.66–0.67]) and ages 9–11 (0.63 [0.62–0.64]). Then it started to increase in adolescence (ages 12–14: 0.71 [0.69–0.72]; ages 15–17: 0.86 [0.84–0.88]) and reached the

Table 2 Medicaid 1915(c) HCBS waiver enrollment rates by cohort characteristics based on annual observations (N = 2,663,460 person-years)

Characteristics: N (%)	ASD waivers	IDD waivers	Other waiver types	No waiver
Total	10,448 (0.4)	298,166 (11.2)	37,895 (1.4)	2,316,951 (87.0)
Age				
Under 6	1,348 (0.2)	19,955 (3.1)	3,850 (0.6)	613,275 (96.1)
6–8	2,180 (0.4)	37,902 (7.5)	7,468 (1.5)	459,183 (90.6)
9–11	1,898 (0.4)	51,280 (10.6)	8,492 (1.8)	421,835 (87.3)
12–14	1,641 (0.4)	57,678 (14.0)	7,310 (1.8)	345,791 (83.8)
15–17	1,642 (0.5)	57,998 (17.5)	5,743 (1.7)	265,791 (80.3)
18–21	1,739 (0.6)	73,353 (25.2)	5,032 (1.7)	211,076 (72.5)
Sex				
Male	8,431 (0.4)	232,086 (11.2)	28,784 (1.4)	1,810,399 (85.7)
Female	2,017 (0.4)	66,080 (11.3)	9,111 (1.6)	506,552 (86.8)
Race/Ethnic group				
White	6,075 (0.5)	160,672 (12.1)	22,649 (1.7)	1,138,031 (85.9)
African American	1,638 (0.4)	30,996 (7.1)	4,212 (1.0)	401,970 (91.6)
American Indian/Alaskan Native	31 (0.1)	1,870 (7.9)	327 (1.4)	21,417 (90.6)
Asian / Native Hawaiian or Pacific Islander	352 (0.7)	14,922 (28.3)	800 (1.5)	36,739 (69.6)
Hispanic/Latino	275 (0.1)	30,687 (12.2)	1,818 (0.7)	219,619 (87.0)
Hispanic/Latino plus one or more races	69 (0.1)	7,382 (7.1)	920 (0.9)	96,075 (92.0)
More than one race	31 (0.2)	1,596 (8.1)	408 (2.1)	17,670 (89.7)
Unknown	1,977 (0.5)	50,041 (11.3)	6,761 (1.5)	385,430 (86.7)

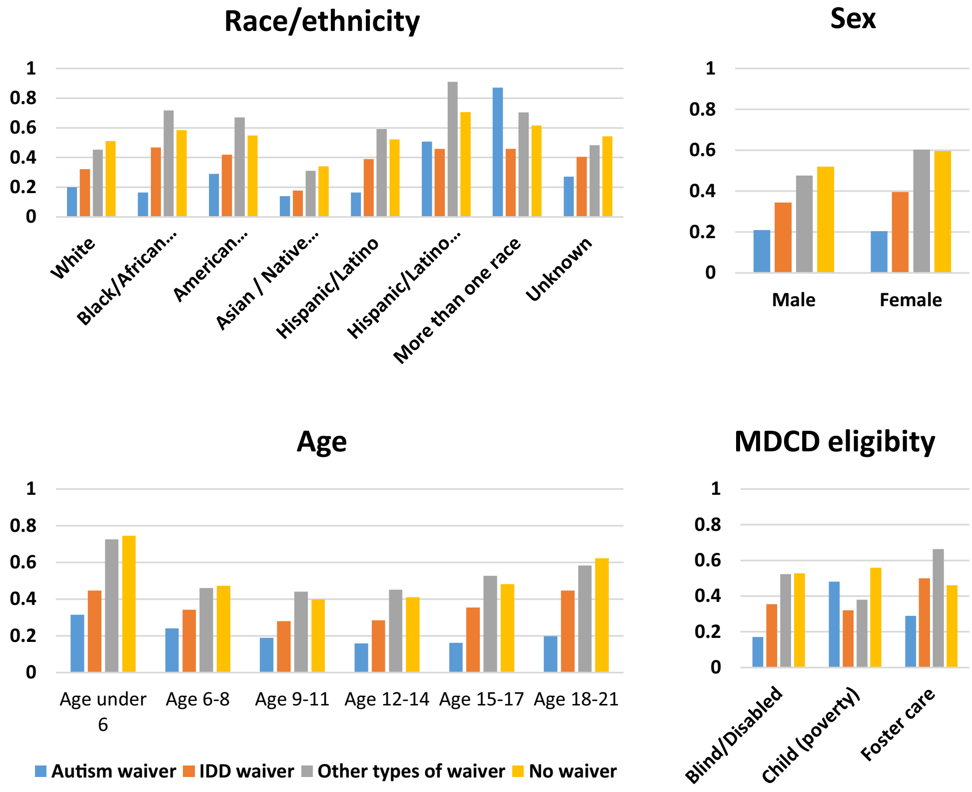

Fig. 1 Average annual incidence of ED visits by waiver type

highest at ages 18–21 (1.12 [1.09–1.15]). Sex, race/ethnicity and Medicaid eligibility were also associated with incidence of ED visits. Being female was associated with a higher incidence of ED visits (1.14 [1.12–1.15]). Compared with White children, African American and American Indian/Alaskan Native children had slightly higher incidence of ED visits. Children who were Asian/Native Hawaiian/Pacific Islander, conversely, had a significantly lower rate of ED visits relative to White children (0.63 [0.61–0.65]). Although Hispanic/Latino children had a rate of ED visits similar to White children, children in the Hispanic/Latino plus one or more other races group had a higher rate of ED visits (1.27 [1.24–1.30]). Children with Medicaid eligibility due to poverty or being in foster care had lower rates of ED visits than those that were blind/disabled (child poverty: 0.87 [0.86–0.87]; foster care: 0.80 [0.79–0.82]).

Discussion

Hospital ED visits may be an indication that regular access to medical care, such as having a primary provider, is not within someone's reach (Centers for Medicare & Medicaid Services, 2021). In our investigation of ASD and IDD waivers and the associated incidence of ED visits, we found a significant association between children's enrollment in an ASD or IDD waiver and lower odds of ED visits, even after adjusting for potential confounders. Similarly, Cidav, Marcus, and Mandell (2014) looked at children's ASD waivers and found that children were more likely to use outpatient services instead of more costly inpatient or long-term care services when compared with two other groups of children.

Better access to critical outpatient, inpatient and psychiatric services is strongly associated with reduced ED visits, which suggests that these services may help prevent or temper crises that can precipitate a visit to the ED (Enard & Ganelin, 2013; Pourat et al., 2015; Tsai et al., 2018). In addition to critical services, ASD waivers provide a wide range of assistance-based services including respite, care support, parent and caregiver training and personal care (Velott et al., 2015), which may help relieve the burden and accompanying stress parents live with as they struggle to access services and care for their children.

Benefits of ASD waivers have been documented in the literature. Previous research has found that parents were less likely to have to quit work to care for their child if the child was enrolled in an ASD waiver (Leslie, Iskandarani, Velott, et al., 2017a, 2017b), and children on more generous waivers had significantly reduced rates of unmet healthcare needs (Leslie, Iskandarani, Dick, et al., 2017a, 2017b). In addition to reduced unmet need for children on more generous waivers, researchers also found an association with significantly reduced odds of having unmet need for Black children with ASD when compared with White children with

Table 3 Multivariable Poisson regression analysis of annual incidence of ED visits

Variables*	Adjusted incidence rate ratios	95% confidence intervals
Annual waiver type		
ASD vs. No waiver	0.58	[0.54–0.63]
IDD vs. No waiver	0.70	[0.68–0.71]
Other vs. No waiver	0.99	[0.95–1.03]
ASD vs. IDD waiver	0.84	[0.77–0.90]
ASD vs. Other waiver	0.59	[0.54–0.64]
IDD vs. Other waiver	0.70	[0.67–0.74]
Age at current year		
Under 6	Reference	
6–8	0.66	[0.66–0.67]
9–11	0.63	[0.62–0.64]
12–14	0.71	[0.69–0.72]
15–17	0.86	[0.84–0.88]
18–21	1.12	[1.09–1.15]
Sex		
Male	Reference	
Female	1.14	[1.12–1.15]
Race/Ethnic Group		
White	Reference	
African American	1.05	[1.04–1,06]
American Indian/Alaskan Native	1.08	[1.03–1.14]
Asian / Native Hawaiian or Pacific Islander	0.63	[0.61–0.66]
Hispanic/Latino	0.97	[0.95–0.99]
Hispanic/Latino plus one or more races	1.27	[1.24–1.30]
More than one race	1.10	[1.06–1.15]
Unknown	0.97	[0.96–0.99]
Medicaid eligibility		
Blind/Disabled	Reference	
Child (poverty)	0.87	[0.86–0.87]
Foster care	0.80	[0.79–0.82]

*The regression model also adjusted for state id, age at cohort entry and year of cohort entry. All variables were statistically significant with p-values < 0.0001

ASD (LaClair et al., 2019). Research also makes clear that waivers that give parents the prerogative to make treatment choices and select care providers, and that empower rather than minimize caregivers' contributions to the process, are associated with higher levels of family wellbeing and lower stress (Eskow et al., 2019; Warfield et al., 2014). While these studies provide evidence regarding the potential pathways by which waivers may reduce ED visits, our findings that waivers indeed are associated with lower rates of ED use do not identify specific causal pathways. Our Medicaid data make identifying use of services that could be on the causal pathway difficult, and thus we focused on identifying the reduced form relationship between ASD waiver enrollment and rates of ED use.

Although waiver enrollment was associated with reduced incidence rates of ED visits among children with ASD, the rates were not consistent across age categories or race/ethnicity. The lowest rate of ED visits was seen in children ages 9–11, but increased with each age group thereafter until reaching the highest rate in the 18–21 age group. The youngest group of children, those in the 0–5 age group, had the next highest incident rate for ED visits. Higher incidence rates in the youngest and oldest children with ASD and differences in ED visits by race/ethnicity require further discussion.

Toddler and Preschool Age Children (0–5 years old)

Children ages 0–5 formed the largest age group in our sample of children with ASD (24% of person-year data), but were the least likely to be enrolled in any of the waivers. As stressed earlier, children benefit tremendously from early diagnosis and evidence-based treatment (Elder et al., 2017). The time period before a child turns five is particularly critical as this is when many of their social and communication skills begin to take form (Koegel et al., 2014; M. E. Yingling & B. A. Bell, 2019; Zwaigenbaum et al., 2015).

In a recent study, Rubenstein and colleagues investigated community-based service use by children with ASD who were ages 3–5. Among the study sample, close to 40% were not receiving community-based services, and children with public insurance were found to receive less services than children with either private insurance or a public/private combination (Rubenstein et al., 2019).

Children with ASD under the age of 6 are typically served in the early intervention system, which is under-resourced such that kids with ASD typically receive about 10–12 h per week of intervention, instead of the recommended 25–40 h per week per EBT protocols (Lee McIntyre & Zemantic, 2017; M. E. Yingling & B. A. Bell, 2019). Looking again at the critical ages of 3–5, Payakachat and colleagues analyzed services received by 2800 children before they entered an autism program and learned that only 28% had received any prior behavioral based treatments (Payakachat et al., 2018). They also found that instead of the recommended 25–40 h per week, less than 30% of children had participated in a service for more than 10 h a week. So while the expectation may be that children through age five are receiving critical recommended services either through an Early Intervention program, the Early and Periodic Screening, Diagnostic and Treatment (EPSDT) program or an alternative program, many children are falling through the cracks. Because of waiting lists and small enrollment limits, it may be particularly difficult for young children to secure a slot on an ASD waiver. And while the IDD waiver appears to be a good alternative as it is also associated with lower rates of ED visits, enrolled children tend to be older (only 7% of enrollees were 5 and under while 25% were 18–21).

Once children enter the educational system, Part B of the Individuals with Disabilities Education ACT (IDEA) becomes very important. As mandated through this legislation, school districts must provide children ages 3–18 who have disabilities with free appropriate public education, referred to as FAPE. Individualized education programs (IEP) are developed to address each child's needs and programs are evaluated on a regular basis to assess the effectiveness of the programs to meet children's needs (Weiss & Mettrick, 2010). Children may receive educational and behavioral support services with embedded speech, occupational and physical therapies among other needed services. In addition, the structure and organization of the school day becomes a part of the treatment environment for youth with ASD. Through this program, over seven million students with some form of disability received at least one service or support during the 2018–2019 school year (U.S. Department of Education Office of Special Education Programs, 2021).

Young Adulthood (18–21 Years Old)

In contrast to the 0–5 age group, young adults in the 18–21 group comprised the smallest number of individuals in our Medicaid sample (11%) yet had the highest enrollment in ASD or IDD waivers overall (25.8%). In spite of heavy waiver enrollment, however, the young adults had the highest incidence rate of ED visits.

There are several factors that may be relevant to our finding of higher incidence of ED visits in young adults. First, ASD is a lifelong condition and symptoms do not remain stagnant over time. As children move into adulthood, many experience mood dysregulation, hypo-activity, and relational problems (Solomon et al., 2012). Older adolescents commonly experience heightened anxiety as they transition to adulthood and struggle through the process of switching from pediatric to adult healthcare providers (Liu et al., 2019; Saqr et al., 2018), making them more prone to ED visits. Second, less regular care occurs as patients age, suggesting that the transition to adulthood could lead to discontinuities in health care for youth making them more susceptible to health emergencies and dependent upon costly treatment (Ames et al., 2020). Finally, schools have been found to be a significant stressor for some children and adolescents and can lead to more frequent visits to the ED (Wharff et al., 2011). Compared with children ages 5–12 with autism, children ages 13–17 with autism were found to be 80% more likely to use inpatient psychiatric hospital care (Mandell et al., 2012). Yet, as students age, they are much less likely to use beneficial in-school services such as one-to-one support (Locke et al., 2017). To address underutilization of services, Kang-Yi and colleagues (Kang-Yi et al., 2016) suggested offering transition care, independent community living, employment readiness and teaching social and communication skills in the school setting.

With respect to race and ethnicity, we found higher ED utilization among non-White groups of children, except for those who were Asian/Native Hawaiian/Pacific Islander or Hispanic/Latino. Compared to White children, the highest ED utilization was observed in the Hispanic/Latino plus one or more races group, while Hispanic/Latino alone had a slightly lower rate of ED visit.

Racial and ethnic disparities among children with ASD have been described in the literature and include delays in diagnosis (Mandell et al., 2010; Shattuck & Grosse, 2007), fewer services received by children with public insurance (Rubenstein et al., 2019), delays in the initiation of early intervention services (Payakachat et al., 2018), and disparities in service utilization rates (Nguyen et al., 2016; Marissa E Yingling & Bethany A Bell, 2019). Together, these disparities may exacerbate symptoms among children and contribute to higher rates of ED visits.

Although collectively a small group of children, the Asian/ Native Hawaiian/Pacific Islander group had the highest percentage of enrollment (29%) in an ASD or IDD waiver, whereas the next two highest groups had less than half that percentage (12.6% of Whites and 12.3% of Hispanic/Latinos were enrolled in either waiver). In addition to hefty enrollment, this group also had the lowest utilization of ED among all race categories. Previous research has also found that Asian/Native Hawaiian/Pacific Islander children did not appear to experience racial disparities in emergency care or health conditions. In a study of US children receiving ED care, Black and Hispanic children were found to experience multiple emergency care disparities when compared with White children but Asian children were not (Zhang et al., 2019). In a large study of racial/ethnic disparities of child health, Asian children reported rates of autism similar to other race/ethnic groups, but reported the least number of adverse health conditions in contrast to Black children who reported the highest prevalence (Mehta et al., 2013).

Although we found the ASD waiver was significantly associated with lower incidence of ED visits among youth with ASD, only 14 states offered this type of waiver during our study period and less than 0.5% of our Medicaid cohort utilized an ASD waiver during our study period. In spite of numerous benefits associated with waiver enrollment, states keep waiver capacity low out of necessity; they are obligated to maintain cost neutrality while providing ASD services, which tend to be costlier than the IDD waiver services. Our analysis revealed that many of the IDD waivers included youth with ASD, and enrollment by children with ASD was associated with reduced ED visits. This is particularly important since IDD waivers tend to have more capacity and are generally less restrictive than a typical ASD waiver.

There are several caveats that must be considered when interpreting the results from our study. First, there is very little random assignment to waivers and consequently this could have introduced selection bias, confounding the study findings. Some states do not give preference to more needy children when filling waiver slots from their waitlists, and although only nine states have adopted a *first-come-first-serve* protocol to select their waiver participants, together these states account for almost 60% of the total waitlist population (Cooper, 2017; MACPAC, 2020; Musumeci et al., 2020). Other states use queuing strategies that give preference to individuals experiencing a crisis or who are in danger of returning to an institutional care facility. This would likely bias estimates of ED use upward, resulting in smaller estimates of the effect size. Second, we used Medicaid MAX data for our analyses; so, as with other claims databases, diagnoses and associated clinical event details are limited. In addition, record entry, coding, and/or other machine/human errors could be possible reasons for misdiagnosis. Together, they can lead to inaccurate identification of ASD diagnosis and co-occurring mental health conditions. To minimize diagnostic uncertainty, subjects were required to have at least 2 separate outpatient diagnoses of ASD on different dates or at least one diagnosis in an inpatient or long-term care setting. Third, because only 14 states offered an ASD waiver during our study period and less than 1% of our cohort utilized one of these waivers, any race/ethnicity analyses must be interpreted with caution. In addition, 17.7% of our sample was recorded as "unknown" for race/ethnicity. Fourth, in part because of limitations in the MAX data regarding the identification of services covered by waivers and used by beneficiaries, we limited our analyses to the identification of associations between waiver enrollment and ED use, leaving estimation of the causal pathways (e.g., how the use of specific behavioral health services played a role in ED use) for future work. Finally, as with all retrospective data analyses, there may be unmeasured confounders and results should be interpreted in that context.

Despite these limitations, our study found that HCBS waivers that served children with ASD, particularly ASD and IDD waivers, were strongly associated with reduced incidence of ED visits. The strength of the association varied across demographic subgroups, with larger effects being seen among Asian/Native Hawaiian/Pacific Islanders, children age 9–11, and those in foster care. These findings support our hypothesis that Medicaid HCBS waivers are associated with reduced incidence of ED visits. Research tends to support the contention that waiver enrollees are better able to access routine, evidence-based services, which in turn helps to reduce the onset of acute adverse events leading to ED visits among children and adolescents with ASD.

Conclusion

Enrollment in ASD and IDD waivers by children with ASD was associated with lower incidence rates of ED visits. These finding are consistent with the intent of HCBS waivers, which is to provide broader and more adequate healthcare services to those in need, thus reducing the need for institutional care. It is also consistent with broader evidence that improved access to needed care can reduce downstream use of acute care. While this study does not identify the kinds of services that lead to reductions in the use of ED services, the results have important implications regarding healthcare costs and outcomes for children with ASD.

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