

Prevalence and Correlates of Educational Intervention Utilization Among Children with Autism Spectrum Disorder

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Abstract This study examined the prevalence and correlates of educational intervention utilization among U.S. preschool aged children with autism spectrum disorder (ASD) prior to recent policy changes. The analysis was based on a nationally representative longitudinal survey of children receiving special education services during the 2003–2004 school year. All children with parent or teacher identified ASD over a 3-year study period were analyzed. Outcomes included utilization of speech therapy, occupational therapy, behavior therapy, and mental health services by service sector. The analysis revealed low rates of behavioral therapy and mental health services. Parents reported that the overwhelming majority of services were received inside school only. This study identified gaps in the provision of services for young children with ASD.

Keywords Autism spectrum disorder · Speech therapy · Occupational therapy · Behavioral therapy · Mental health services · Preschool children

Introduction

Children with autism spectrum disorder (ASD) use a variety of services in both the health care and education systems to meet their developmental needs. ASD-specific educational interventions address core features of ASD including delayed language development, patterns of repeated and repetitive behavior, and difficulty with social interaction. Prior research has documented greater unmet need for general health care services for children with ASD compared with other children with special health care needs (Kogan et al. 2008), but historical data on use of specific ASD treatments is lacking. In particular, major national data sets used to monitor the parent-reported prevalence of ASD or need for health services have only recently begun to measure rates of key ASD-specific educational interventions¹ such as speech therapy, occupational, therapy, social skills training, and behavioral modification, including applied behavior analysis (ABA). Lack of data on utilization of ABA and other behavioral therapies is particularly problematic because these therapies have the most robust evidence base for their effectiveness, and as such policy makers have an incentive to monitor trends in utilization.

In response to the rising prevalence of autism and growing awareness of evidence-based treatments, major policy changes have aimed to increase access to ASD educational interventions. Most of the policies focus on the supply of ABA services as well as ameliorating barriers to access through private health insurers. To date, 41 states have adopted autism insurance mandates that require

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¹ Although the term “educational intervention” is used to identify these non-medical treatments for ASD, services can be delivered both inside and outside of school.

private health insurers to provide access to ASD-specific educational interventions (Autism Speaks 2015). Mandates range from the more generous, with no age or dollar limit on coverage, to the less generous, with annual caps of \$30,000 on ABA services for 3 years. The intent of the mandates was to increase access and reduce well-documented family financial burden (Cidav et al. 2012; Kogan et al. 2008; Liptak et al. 2006; Montes and Halterman 2008; Parish et al. 2015; Shimabukuro et al. 2008). However, it is conceptually unclear whether these ASD-specific interventions constitute medical or educational interventions (Holland 2010), and thus whether health insurers or school systems should be primarily responsible for insuring access and funding.

Without historical data on the utilization of key ASD-services by sector, it is difficult to assess whether policy changes aimed at increasing access through private health insurance are warranted. Furthermore, without a historical understanding of sector-specific rates of service use, it is difficult for policymakers to assess the potential impact of other policy changes, such as those that increased the availability of ABA services within school districts and those that increased the supply of board-certified behavior analysts.

Ultimately, the multi-sector nature of ASD educational interventions offers a variety of policy solutions of which state mandates are only one. Historical data on the distribution of services prior to the recent policy changes can advance policymakers' understanding of the optimal distribution of resources across sectors. By understanding how and where children used ASD-specific educational interventions prior to the current policy changes, we can advance the discussion of policy solutions that yield the greatest gains in efficiency and effectiveness for children with ASD.

This study provides such a baseline. We document nationally representative rates of utilization of ASD-specific educational interventions, including behavioral therapy, speech therapy, occupational therapy, and mental health services during preschool and early elementary school (ages 3–7) over three academic years (2003–2004, 2004–2005, 2005–2006). We focus on the preschool and early elementary school years for two reasons. First, the median age of ASD diagnosis is 4.4 years; thus, initiation of treatment is most relevant to this age range (CDC 2014). Second, prior research has shown that the economic burden of ASD treatment on families is greatest during this period (Buescher et al. 2014; Ganz 2007). We answer two research questions. First, what are the rates of service use by service setting among preschool and early elementary school aged children with ASD? Second, do rates of service use overall or in both settings (school and outside school) differ by socioeconomic characteristics of children, families, and communities?

Methods

Data Source

The data for this study came from the Pre-Elementary Education Longitudinal Study (PEELS), a 6-year longitudinal panel study of children receiving preschool special education services. Beginning in the 2003–2004 school year, a nationally representative sample of 3104 children was drawn and followed over five waves of data collection. Data from multiple informants were collected including parents, teachers, and students. This study relied on data from the first three waves of parent and teacher questionnaires (i.e. 2003–2004, 2004–2005, and 2005–2006 school years) from which we drew on detailed reports of services received both inside and outside the classroom.

The PEELS used a two-stage sample design. A national sample of local education agencies (LEAs) was drawn in the first stage and a sample of preschoolers with disabilities was drawn in the second stage from participating LEAs. The initial sample was supplemented in Wave 2 due to a serious under-coverage in one region of the country. Details of the supplemental sample can be found elsewhere (Carlson et al. 2008).

Parent, teacher, and LEA data were used in the study. Parent/guardian interviews were administered through a computer assisted telephone interview. Response rates for the parent interview were high with 96 % participating in wave 1, 93 % in wave 2, and 88 % in wave 3. Accommodations for the parent interview included Spanish language administration and use of TTY or a relay service for the hearing impaired. Mail questionnaires were used to collect data from teachers and LEAs. Response rates for the teacher questionnaire were 76 % in wave 1 and 84 % in waves 2 and 3. LEAs were sent questionnaires to collect information about policy and practice in wave 1 only with a response rate of 90 %.

Study Population

The subsample of children receiving service for ASD was identified through parent and teacher reports as well as a derived disability field included in the PEELS dataset. There were 250 children with ASD identified at some point over the first three waves that we used in the longitudinal data analysis. Of the 250, over 50 % were identified as having ASD by multiple sources. Only 60 children did not have a parent report of ASD at least once over the study period. Although neither the parent nor teacher reports of ASD are based on standardized diagnostic instruments, previous epidemiological research finds that administrative classifications such as special education category and ICD-

9 codes are reliable predictors of clinically identifiable ASD (Yeargin-Allsopp et al. 2003; CDC 2012; Burke et al. 2014). Use of these data are governed by a data use agreement with the U.S. Department of Education, and all unweighted sample sizes are rounded to the nearest 10 as required by the agreement. The Institutional Review Board of Northern Illinois University approved the research study.

Outcome Measures

We selected four services as dependent variables from 23 services reported in the PEELS. The four included speech therapy, occupational therapy (including sensory integration therapy), behavior therapy, and mental health services. For three of the four services, we used reports by both parents and teachers to identify service use. Behavior therapy relied only on parent reports because teachers were not asked about the receipt of behavior therapy. Mental health services combined multiple response options including social work, psychological, and mental health services. We selected services that were among the evidence-based, educational interventions recommended by the American Academy of Pediatrics (Myers and Johnson 2007). High frequency services that may be important for the treatment of ASD but excluded from the analysis include instruction with a special educator, paraprofessional classroom assistance (aide), and tutoring services. For each service, we constructed a four-level response variable to indicate the receipt of service by setting: service received inside and outside of school, only at school, only outside of school, none received.

Individual, Family, and Community Variables

Child, family, and local education agency characteristics were used as independent variables in the analysis. Child characteristics include sex, age (at wave 1), race and ethnicity (Hispanic, African American, or White), severity of disability, and health insurance type (private, public, uninsured, and multiple coverage). The severity of disability reflects an index built from an analysis of 15 domains of child functioning and has been described in detail elsewhere (Daley et al. 2009). In the analysis, the continuous severity index was categorized in quartiles defined using the entire sample. Family characteristics were included to reflect the social, human, and economic capital available to the family. We used annual family income (<\$25, 25–50, >50 K), mother's education (high school diploma or less, more than high school diploma), and mother's marital status (married versus not married). Finally, we incorporated characteristics of the LEA in order to identify community level correlates of treatment access.

Local education agency characteristics include the district size (very large, large, medium, small), district wealth (very low poverty, low poverty, medium poverty, high poverty), and metropolitan status (urban, suburban, rural).

In the multivariate analysis, we dichotomized several independent variables in order to assess the significance of the category of greatest substantive interest. African American and Hispanic children were combined into a single category representing non-white children and were compared with white children. Although the diagnostic experiences of Latino children have been shown to differ from non-Latino white children (Magaña et al. 2013), key statistics such as prevalence find greater rates of ASD among white children compared with both African American and Latino children (CDC 2014). Children insured exclusively through public health insurance were compared with all other forms of insurance or lack of insurance. Household income was dichotomized in order to compare the highest socioeconomic households with all others (\geq \$50 K annual income vs. <\$50 K). Finally, we dichotomized LEA district size and wealth measures in order to compare very large and very low poverty districts with all others. Each of our multivariate models was also run with non-dichotomized versions of these independent variables, and no statistically significant results were masked by the dichotomization.

Statistical Analysis

Because of the complex sampling design, sample weights were included in the data set for different types of data analysis. Although there were 3104 children included in the original sample only 2010 observations were available for longitudinal data analysis involving parent and teacher data across waves 1–3. The longitudinal weights permitted inference over time for the population of children ages 3–5 receiving special education services in the 2003–2004 school year.

The PEELS provided some imputation of missing data within the restricted use data set. Because rates of missing data were above acceptable levels (>10 %) for some independent variables, we used multiple imputation to consistently address the problem of missing data. We fit separate imputation models for each of our dependent variables using the method of sequential chained equations. We allowed the predictors to vary across variables included in the model. For each dependent variable, we created 20 data sets with no missing data. Multiple imputation was performed using Stata version 13.

Univariate and multivariate analyses were performed using the first three waves of the PEELS. Logistic regression was used for the multivariate analysis. Because the goal of the analysis was to make inferences about the

population-average effect of each independent variable on the outcomes, we fit logistic models with generalized estimating equations (GEE). GEE coefficients used a working independence correlation structure while variance estimates used the Huber White sandwich estimator. All analyses were performed using Sudaan software for multiply imputed data with the Taylor series linearization method design options.

Results

Table 1 presents the descriptive statistics of the study population in the 2003–2004 school year (baseline). Consistent with surveillance data, our study population included over 5 times more boys than girls. The majority of the sample was white, with lower severity of disability, covered by health insurance, and living with married mothers with some postsecondary education in urban or suburban settings. Over 40 % of the sample was age 4 at baseline, and nearly 40 % lived in families with annual incomes over \$50,000. Approximately one-third of the sample lived in very large and very low poverty school districts.

Trends in treatment utilization over time vary by type of service (Table 2). Speech therapy was the most common treatment at baseline. Approximately 93 % of all students with ASD receive this service and the majority does so at school only (77 %). After 3 years, only 75 % of students received speech therapy, and were more likely to receive it both inside and outside of school ($p < 0.01$). Only 65 % of students received occupational therapy and the rates did not significantly vary over time. The percent of children receiving behavior therapy and mental health services was substantially lower. Less than 6 % of preschool aged children with ASD received behavior therapy at baseline. Those that received behavior therapy were most likely to do so outside of school (3.7 %). Only 11 % of children received mental health services at baseline and were most likely to receive this service at school (7.4 %). There was no association between survey wave and either behavior therapy or mental health services.

The multivariate analysis was performed to estimate the adjusted odds of receiving any of the four services (Table 3) or of receiving the service both inside and outside of school (Table 4). Severity of disability and child's age were the only variables associated with odds of receiving service regardless of sector in Table 3. None of the four services were associated with socioeconomic characteristics at the child, family, or school district level.

We did find socioeconomic correlates of receipt of speech and occupational therapy both inside and outside of school (Table 4). Children with family income above \$50 K had 3.00 times the odds ($p < 0.01$) of receiving

Table 1 Characteristics of children with autism spectrum disorders from Wave 1 of the Pre-Elementary Education Longitudinal Study

	Weighted%	
	(95 % confidence interval)	
<i>Child characteristics</i>		
Gender		
Male	83.6	(76.2–89.1)
Female	16.4	(10.9–23.8)
Age		
Age 3	21.7	(15.7–29.2)
Age 4	42.6	(34.5–51.1)
Age 5	35.7	(27.9–44.4)
Race/ethnicity		
Hispanic	21.2	(14.8–29.5)
African American	6.8	(3.5–12.8)
White	72.0	(62.7–79.8)
Severity of disability		
1, Least severe quartile	44.8	(36.5–53.3)
2	17.3	(12.4–23.6)
3	17.0	(12.0–23.6)
4, Most severe quartile	21.0	(15.0–28.6)
Health insurance status		
Private	50.4	(41.4–59.4)
Public	25.8	(18.4–34.8)
Uninsured	3.2	(1.2–8.5)
Multiple coverage	20.6	(13.8–29.6)
<i>Family characteristics</i>		
Income, \$		
≤25,000 per year	34.2	(26.1–43.3)
25,000–50,000 per year	26.9	(20.6–34.2)
>50,000 per year	39.0	(30.1–48.7)
Mother's education		
High school diploma or less	37.2	(28.8–46.5)
More than high school diploma	62.8	(53.5–71.2)
Mother married		
No	25.8	(19.6–33.1)
Yes	74.3	(66.9–80.4)
<i>Local education agency characteristics</i>		
District size		
Very large	31.3	(21.6–43.0)
Large	24.2	(17.3–32.9)
Medium	23.9	(16.1–34.0)
Small	20.5	(14.1–28.9)
District wealth		
Very low poverty	30.5	(21.0–41.9)
Low poverty	19.0	(12.0–28.8)
Medium poverty	30.9	(20.3–43.9)
High poverty	19.7	(10.8–33.1)
Metro status		
Urban	43.4	(31.4–56.3)

Table 1 continued

	Weighted%	
	(95 % confidence interval)	
Suburban	43.7	(32.1–56.0)
Rural	12.9	(7.3–22.0)

occupational therapy both inside and outside of school, while children whose mother had some postsecondary education were significantly more likely to receive speech therapy in both settings (adjusted odds ratio 3.33, $p < 0.05$) compared with mothers having a high school education or less.

Discussion

Prior to policy designed to increase access to ASD services, the vast majority of children with ASD receiving preschool special education services did not receive behavioral therapies or mental health services either inside or outside of school. We find that only 5.6 % of 3–5 year olds with ASD received behavior therapy and 11.3 % received some mental health or social work service during the 2003–2004 school year. In contrast, we find that large proportions received speech and occupational therapy and did so predominately at school. The low rates of behavioral therapy are particularly troubling given that these services, particularly early intensive behavioral interventions (EIBI), are the most widely recommended evidence-based treatment for ASD (Lovaas 1987; McEachin et al. 1993; Rogers 1998; Smith et al. 1997; Vismara and Rogers 2010).

Barriers to behavioral therapy including ABA were known to exist both in the education and health care settings. At school, behavior therapists often had large case-loads. Behavioral therapy often fell on the special educator who may not have been trained in these techniques and may not have involved parents in teaching (Love et al. 2009; Reichow and Wolery 2009). In the health care setting, lack of access to ABA and other behavioral therapies through private and public health insurance has been well documented by advocates and parents (Autism Speaks 2015; Corcoran et al. 2015). Barriers imposed by private insurers were largely responsible for the advocacy that led to state autism insurance mandates. Public insurers were also limited in the ability to offer behavioral therapies to children with ASD. Medicaid 1915(c) home and community based services waivers have historically been the means of providing such services. A recent study of these waiver programs found that they differed substantially across states and in the type and scope of services covered

(Velott et al. 2015). With the passage of the Affordable Care Act, states were given more options to expand home and community-based services to all Medicaid enrollees (Association of Maternal and Child Health Programs 2012). The extent to which states take up this option or provide ABA coverage through Medicaid programs has been limited (Mann 2014).

The very low rates of behavioral therapy are consistent with limited previous research documenting unmet specialty and therapy needs among children with ASD (Brown et al. 2012; Chiri and Warfield 2012; Farmer et al. 2014). It is noteworthy that rates of behavioral therapy utilization in the PEELS data are much lower than recent rates reported in the Survey of Pathways to Diagnosis and Service (“Pathways”) conducted by the National Center for Health Statistics for children ages 6–17 (Pringle et al. 2012). Parents in the Pathways survey reported that 40 % of children ages 6–11 with special health care needs and ASD currently used behavioral intervention or modification services compared with our rates of less than 6 %. Even if estimates from the Pathways data are accurate for children in early elementary school, over half of children with ASD are still not receiving the most evidence-based type of therapy. Our data suggest that in preschool far fewer did so.

Our analysis by service setting confirms that most young children with ASD receive educational interventions only at school. The goal of school based services is to provide students with disabilities a “free and appropriate public education” (FAPE) that meets the unique needs of students and prepares them for further education, employment, and independence (*Education for All Handicapped Children’s Act 1975, Individual with Disabilities Education Act 1990, Individual with Disabilities Education Act 1997*); however, the degree to which the unique needs of students with ASD are met varies and depends in part on the legal definition of FAPE. This definition established by the US Court of Appeals states that FAPE is “a serviceable Chevrolet and not a Cadillac” (United States Court of Appeals, Sixth Circuit 1993). This definition does not ensure that this level of service will prepare children for further education, employment, and independence.

Receiving service outside of school was relatively rare prior to state insurance mandates. The highest percent of children receiving service both inside and outside of school was just 13 % (speech therapy at wave 3). At the time of data collection for the PEELS, only one state had an autism insurance mandate in effect. Given the very low rates of service use outside of school, how much would mandates need to increase access to reduce unmet need for services? Research on the causal effect of autism insurance mandates is in its’ infancy. To our knowledge, a recent analysis by Chatterji et al. (2015) is the first to use national data to address this question. Using multiple years of data from the

Table 2 Treatment service utilization by sector for children with autism spectrum disorders from Wave 1–3 of Pre-Elementary Education Longitudinal Study

Treatment service	Weighted%			<i>p</i> value
	(95 % confidence interval)			
	Wave 1	Wave 2	Wave 3	
<i>Speech therapy</i>				
None	7.0 (2.8–16.3)	18.2 (12.1–26.4)	25.9 (18.5–35.0)	0.01
Only at school	80.0 (71.1–86.7)	68.9 (60.2–76.4)	60.1 (51.2–68.4)	
Only outside school	^a	2.7 (1.3–5.4)	^a	
Both inside and outside school	12.7 (8.0–19.6)	10.2 (6.3–16.1)	13.1 (8.6–19.3)	
<i>Occupational therapy</i>				
None	34.7 (26.8–43.6)	39.7 (32.1–47.8)	43.0 (35.4–50.9)	0.44
Only at school	54.8 (44.9–64.3)	51.8 (43.8–59.7)	48.0 (39.7–56.4)	
Only outside school	3.6 (1.2–10.7)	^a	^a	
Both inside and outside school	6.9 (3.4–13.5)	6.7 (3.2–13.4)	7.9 (3.8–15.5)	
<i>Behavioral therapy (ABA, Lovaas)</i>				
None	94.4 (88.3–97.4)	94.3 (90.9–96.5)	93.0 (88.9–95.6)	0.61
Only at school	1.4 (0.3–6.2)	2.0 (0.7–5.8)	1.5 (0.5–3.9)	
Only outside school	3.7 (1.7–7.7)	3.7 (2.3–6.0)	5.6 (3.3–9.2)	
Both inside and outside school	^a	^a	^a	
<i>Mental health therapy (including social work)</i>				
None	88.7 (83.3–92.6)	90.8 (86.0–94.1)	90.9 (85.8–94.3)	0.55
Only at school	7.4 (4.4–12.0)	6.4 (3.6–11.0)	4.8 (2.5–8.8)	
Only outside school	2.8 (1.1–6.9)	1.9 (0.8–4.3)	4.2 (2.2–8.1)	
Both inside and outside school	^a	0.9 (0.3–3.3)	^a	

P values refer to Pearson Chi square tests of association between service and survey wave

^a Estimates suppressed because of sample sizes <4

National Survey of Children with Special Health Care Needs, the authors find no statistically significant relationship between state ASD mandates and financial burden, access to care, and unmet need for services. Because the survey captures information about unmet need for children with all types of special health care needs, questions on services do not specify ABA or other behavioral therapies. Instead, the authors examined whether state ASD mandates were associated with unmet need for speech, occupational,

or physical therapy or unmet need for mental health care or counseling due to costs or insurance issues. They find no effect.

Our findings cannot determine whether the lack of services outside of school signals unmet needs, or conversely whether the receipt of services in multiple settings signals a comparative advantage over other children. Unequal access to EIBI prior to or during preschool may impact the types of services received outside of school. While the research

Table 3 Logistic regression models predicting any service use for children with autism spectrum disorders from Wave 1–3 of Pre-Elementary Education Longitudinal Study

	Odds ratio (95 % confidence interval)							
	Any speech therapy		Any occupational therapy		Any behavior therapy		Any mental health therapy	
<i>Child characteristics</i>								
Gender								
Male	1.00	(Reference)	1.00	(Reference)	1.00	(Reference)	1.00	(Reference)
Female	0.76	(0.30–1.94)	0.96	(0.45–2.05)	0.13**	(0.03–0.56)	0.39	(0.13–1.18)
Age								
Age 3	1.00	(Reference)	1.00	(Reference)	1.00	(Reference)	1.00	(Reference)
Age 4	0.55	(0.22–1.39)	0.65	(0.32–1.34)	0.73	(0.30–1.82)	0.85	(0.47–1.52)
Age 5	0.36*	(0.14–0.91)	0.69	(0.32–1.50)	0.63	(0.27–1.45)	0.92	(0.40–2.11)
Race/ethnicity								
White	1.00	(Reference)	1.00	(Reference)	1.00	(Reference)	1.00	(Reference)
Non-White	1.23	(0.42–3.59)	0.76	(0.28–2.07)	0.55	(0.17–1.73)	0.60	(0.29–1.28)
Severity of disability								
1, Least severe quartile	1.00	(Reference)	1.00	(Reference)	1.00	(Reference)	1.00	(Reference)
2	2.26	(0.76–6.71)	2.17	(0.99–4.77)	1.29	(0.52–3.23)	1.88	(0.87–4.06)
3	3.11*	(1.11–8.70)	3.51**	(1.37–8.96)	2.15	(0.88–5.25)	1.94	(0.88–4.28)
4, Most severe quartile	6.50*	(1.55–27.32)	8.67***	(2.90–25.91)	0.87	(0.25–3.07)	1.80	(0.82–3.91)
Health insurance status								
Private, uninsured, multiple insurance	1.00	(Reference)	1.00	(Reference)	1.00	(Reference)	1.00	(Reference)
Public	0.88	(0.34–2.27)	0.82	(0.39–1.73)	0.81	(0.27–2.44)	1.07	(0.53–2.15)
<i>Family characteristics</i>								
Income, \$								
<\$50,000 per year	1.00	(Reference)	1.00	(Reference)	1.00	(Reference)	1.00	(Reference)
≥50,000 per year	1.00	(0.34–2.95)	1.26	(0.72–2.22)	1.36	(0.72–2.56)	1.28	(0.67–2.43)
Mother's education								
Less than high school diploma	1.00	(Reference)	1.00	(Reference)	1.00	(Reference)	1.00	(Reference)
High school diploma or more	1.05	(0.44–2.51)	1.44	(0.79–2.63)	1.70	(0.68–4.25)	0.81	(0.38–1.77)
Mother married								
No	1.00	(Reference)	1.00	(Reference)	1.00	(Reference)	1.00	(Reference)
Yes	1.48	(0.65–3.36)	1.46	(0.73–2.92)	0.83	(0.32–2.19)	0.62	(0.30–1.27)
<i>Local education agency characteristics</i>								
District size								
Large, medium, small	1.00	(Reference)	1.00	(Reference)	1.00	(Reference)	1.00	(Reference)
Very large	1.11	(0.49–2.52)	0.79	(0.36–1.73)	0.99	(0.34–2.87)	1.24	(0.42–3.61)
District wealth								
Low, medium, high poverty	1.00	(Reference)	1.00	(Reference)	1.00	(Reference)	1.00	(Reference)
Very low poverty	1.22	(0.52–2.86)	1.07	(0.46–2.48)	0.66	(0.21–2.06)	1.23	(0.52–2.89)
Metro status								
Urban	1.00	(Reference)	1.00	(Reference)	1.00	(Reference)	1.00	(Reference)
Suburban	1.19	(0.56–2.53)	0.87	(0.38–2.03)	0.66	(0.20–2.12)	1.23	(0.46–3.26)
Rural	1.02	(0.30–3.47)	0.92	(0.29–2.88)	0.71	(0.18–2.73)	0.86	(0.26–2.90)

Odds ratios and confidence intervals based on GEE logistic regression with variance estimates based on the Huber White sandwich estimator. The non-white race-ethnicity category combines African American and Hispanic children

*** $p < 0.001$; ** $p < 0.01$; * $p < 0.05$

Table 4 Logistic regression models predicting service use inside and outside school for children with autism spectrum disorders from Wave 1–3 of Pre-Elementary Education Longitudinal Study

	Odds ratio (95 % confidence interval)			
	Speech therapy service inside and outside school (vs. only inside)		Occupational therapy service inside and outside school (vs. only inside)	
<i>Child characteristics</i>				
Gender				
Male	1.00	(Reference)	1.00	(Reference)
Female	0.91	(0.35–2.37)	1.11	(0.33–3.67)
Age				
Age 3	1.00	(Reference)	1.00	(Reference)
Age 4	1.07	(0.43–2.65)	0.66	(0.21–2.09)
Age 5	1.52	(0.57–4.07)	0.92	(0.35–2.38)
Race/ethnicity				
White	1.00	(Reference)	1.00	(Reference)
Non-White	0.69	(0.24–1.98)	0.87	(0.26–2.89)
Severity of disability				
1, Least severe quartile	1.00	(Reference)	1.00	(Reference)
2	1.07	(0.43–2.69)	2.20	(0.50–9.60)
3	1.22	(0.41–3.57)	1.83	(0.48–6.98)
4, Most severe quartile	2.81*	(1.06–7.47)	4.18*	(1.29–13.62)
Health insurance status				
Private, uninsured, multiple insurance	1.00	(Reference)	1.00	(Reference)
Public	1.23	(0.51–2.96)	0.53	(0.18–1.57)
<i>Family characteristics</i>				
Income, \$				
<\$50,000 per year	1.00	(Reference)	1.00	(Reference)
≥50,000 per year	1.72	(0.81–3.66)	3.00**	(1.34–6.73)
Mother's education				
Less than high school diploma	1.00	(Reference)	1.00	(Reference)
High school diploma or more	3.33*	(1.23–9.01)	2.89	(0.75–11.07)
Mother married				
No	1.00	(Reference)	1.00	(Reference)
Yes	1.09	(0.40–2.95)	0.69	(0.21–2.29)
<i>Local education agency characteristics</i>				
District size				
Large, medium, small	1.00	(Reference)	1.00	(Reference)
Very large	2.34*	(1.02–5.34)	2.61	(0.62–10.98)
District wealth				
Low, medium, high poverty	1.00	(Reference)	1.00	(Reference)
Very low poverty	1.12	(0.46–2.71)	1.22	(0.34–4.47)
Metro status				
Urban	1.00	(Reference)	1.00	(Reference)
Suburban	1.44	(0.55–3.78)	2.19	(0.58–8.33)
Rural	0.35	(0.05–2.54)	0.58	(0.07–5.17)

Odds ratios and confidence intervals based on GEE logistic regression with variance estimates based on the Huber White sandwich estimator. The non-white race-ethnicity category combines African American and Hispanic children

*** $p < 0.001$; ** $p < 0.01$; * $p < 0.05$

evidence continues to grow in support of the benefits of EIBI, it is unknown how these types of interventions ameliorate the need for some services upon entry to school or during the early elementary school years (Reichow et al. 2012). The lack of services received outside of school may also signal deficits of care coordination. Although recommendations can be made, neither school-based professionals nor health care system based practitioners have the authority to dictate what services are received outside of their own setting. This siloed approach to treatment planning may contribute to the socioeconomic differences that we found in the rates of receiving speech and occupational therapies in both settings. In the healthcare system, patient centered medical homes offer a model for the delivery of primary care that may help to address the care coordination needs of many children with ASD; however, considerable challenges remain including the pediatrician's lack of time, training, resources, and authority outside of the healthcare system (Carbone et al. 2010; Hyman and Johnson 2012).

We find socioeconomic correlates of service use only after accounting for service setting. High maternal education and family income are both associated with greater odds of receiving speech and occupational therapies in the education and healthcare systems. This finding provides some of the first evidence that families with socioeconomic advantage were securing more services for their children and is consistent with findings of service engagement among young adults with ASD (Shattuck et al. 2011). While we cannot assess the significance of this disparity for long-term child outcomes, future comparative effectiveness research can help shed light on which combinations and quantities of services produce the best outcomes. This goal is consistent with the 2013 strategic plan of the Interagency Autism Coordinating Committee with respect to the need for studies that assess the effectiveness of interventions or services in broader community settings (Interagency Autism Coordinating Committee (IACC) 2014).

To our knowledge this is the first study to present nationally representative rates of educational intervention use for preschool aged children with ASD. Not only is the study nationally representative, it represents a significant proportion of the nation's young children with ASD. Although there is no direct way to estimate the proportion of 3–5 year old children with ASD in 2003 enrolled in preschool special education, we were able to compare the estimated size of the population of children with parent reported ASD from the 2003 National Survey of Children's Health (NSCH) with our estimated population size from the PEELS. The two sources yielded very similar population sizes suggesting that most 3–5 year old children with ASD participate in preschool special education (48,000 aged 3–5 with parent-reported ASD in the NSCH (author's calculations) vs. 45,000 in the PEELS).

The strengths of the study are balanced by some weaknesses. The variables available in the PEELS data imposed some limits on our analysis. First, we had to rely on parent and teacher identified ASD to define the study population rather than a more standard measure such as results from the Autism Diagnostic Observation Schedule or the Autism Diagnostic Interview, Revised. There are well known limitations of administrative indicators of ASD prevalence in special education populations (Shattuck 2006). The extent to which preschool aged children are served under administrative categories such as "developmental delay" rather than ASD may impact the likelihood that children with ASD receive needed ASD-specific behavioral interventions and thus contribute to the low prevalence of such therapies at school. In addition, the questions used to identify the type of health insurance in the PEELS study were broad and may have under identified the use of public health insurance. We applied a strict definition of public health insurance in our analysis and may have underestimated effects of public health insurance. A third weakness stemming from the data was the lack of specificity in the wording of the behavioral therapy question. Although there was an interviewer note to clarify that ABA and Lovaas were types of behavior therapy, it is unknown whether all respondents heard the note. Finally, we were unable to use paternal characteristics in our models. Recent research suggests that paternal age is an important risk factor for offspring ASD (Hultman et al. 2011). We focused on maternal rather than paternal characteristics in our models because paternal characteristics were not included among a set of derived variables in the PEELS data.

Another type of limitation stems from the decision to measure the prevalence of educational interventions without controlling for classroom settings. For example, behavioral therapy in a specialized classroom for autism may mean something very different than behavioral therapy delivered to a child in a mainstream setting. We opted to measure the prevalence of service without adjusting for any contextual aspects of the service setting in order to provide easily interpretable rates of service utilization. In this way, our utilization rates are most similar to the data now available through the Pathways survey. Unlike the Pathways data, which contains information about diagnostic experiences and service use for children ages 6–17 with special health care needs, our estimates reflect service use under the age of 6.

The majority of young children with ASD did not receive behavior therapy or mental health services during the preschool and early elementary school years prior to recent policy changes. Given that behavior therapy is the most evidence-based treatment available for children with ASD, low rates of utilization are concerning and beg the

question whether state ASD mandates to increase access through private health insurance are sufficient or efficient policy changes. Strengthening schools' capacity to deliver service and increasing families' ability to access these services in the home are other options for policy change. Home-based behavioral services may be particularly beneficial because they provide an efficient way to train and educate parents and other caregivers, and thus translate important tools for behavioral control to the home. More research is needed to determine to what extent, if any, service delivery has improved since the collection of this data and whether state mandates or other changes designed to increase access and utilization of services have had the intended effect of helping young children with ASD reach their full developmental potential.

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Author Contributions LB conceived of the study, conducted the data analysis, participated in the interpretation of the data, and drafted the manuscript; LC participated in the interpretation of the data and helped to draft the manuscript; AC participated in the interpretation of the data and helped to draft the manuscript. All authors read and approved the final manuscript.

Compliance with Ethical Standards

Conflict of interest The authors declare that they have no conflicts of interest.

Ethical Approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. This project was approved by the institutional review board at Northern Illinois University.

Informed Consent Informed consent was obtained from all individual participants included in the study.

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