

Parent-Reported Use of Interventions by Toddlers and Preschoolers With Autism Spectrum Disorder

Nalin Payakachat, Ph.D., J. Mick Tilford, Ph.D., Karen A. Kuhlthau, Ph.D.

Objective: This study examined services used by young children with autism spectrum disorder (ASD) and factors associated with use.

Methods: A retrospective observational study was conducted with baseline data for toddlers (under age three) and preschoolers (three to less than six years) with ASD enrolled in the Autism Speaks Autism Treatment Network registry from 2008 to 2013 (N=2,804). Parents' reports at enrollment of services received by children were documented. Factors associated with service use and with hours per week of services used were identified by multiple regression analyses.

Results: At baseline, 79% of children had received at least one service; 28% had received behavioral services. In the sample, less than 30% of children who received at least one service spent more than ten hours per week in any service

use. Children who received services were more likely to be of white race and to have had an ASD diagnosis prior to registry enrollment. Age, previous ASD diagnosis, maternal education, and child's IQ were significantly associated with the use of behavioral services; IQ was negatively associated with use. A consistent trend toward greater use of behavioral services was found over the study period. Factors associated with hours of any services used per week included age, gender, race, maternal education, and clinical characteristics. The predicted average weekly service hours for children with ASD across registry sites ranged from 3.1 ± 1.0 to 9.5 ± 2.1 .

Conclusions: Service use varied according to child, family, and system characteristics. More efforts should be focused on early intervention and on children with ASD who have low socioeconomic status and cognitive disability.

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The increased prevalence of autism spectrum disorder (ASD) among children has created a demand for effective interventions to address the core impairments and myriad comorbid conditions associated with ASD (1). Children with ASD exhibit impaired social communication and social interaction skills (2). They can also have atypical patterns of behavior and interest, along with restrictive, repetitive, and stereotypical behaviors. Diagnosis of ASD can be accurately verified among children as young as 24 months (3). A number of studies have documented that the diagnosis of ASD varies according to several factors (4,5), including race-ethnicity, socioeconomic status, location, and the clinical characteristics of the child (6–8). Even with early diagnosis, treatment may vary considerably on the basis of these factors, which can affect both the child with ASD and his or her family (9).

Although there is no cure for ASD, evidence supports the use of behavioral interventions and other services to improve outcomes for children with ASD (10–14). However, evidence regarding factors associated with use of interventions is limited. Studies suggest that significant disparities exist in the receipt of effective services, especially behavioral interventions (15–17). A major concern is that children of all backgrounds, and especially disadvantaged backgrounds, are not

receiving behavioral interventions and other services necessary to address the core symptoms and the myriad comorbid conditions associated with ASD. Nguyen and colleagues (16) used data from an ongoing case-control study in a single state to examine disparities in service utilization. Although they showed that use of services differed by socioeconomic characteristics, the children in the sample already had a diagnosis of ASD and their enrollment in an ongoing study meant that they differed considerably from children in the general population, who face substantial barriers to receiving care. A study in Canada found that behavioral interventions were reported for 28% of children at a baseline visit and that the proportion increased to 59% in the following 12 months (18). A large survey of children with special health care needs found that 38% to 44% of children identified as having ASD received community-based behavioral interventions (19). Kang-Yi and colleagues (20) examined use of behavioral services among children with mental illnesses enrolled in Medicaid and showed that those with ASD used more services than children with other conditions.

Information is needed on use of behavioral and other services by children with ASD in relation to clinical and socioeconomic characteristics across a broad geographic range.

Better understanding of service use among young children (under age six) with ASD may inform the design of policies ensuring that all children with ASD receive recommended interventions. The National Research Council (21), as well as leading autism advocacy and support organizations, recommends that children with ASD receive “structured, therapeutic activities for at least 25 hours per week.” The number of children meeting this recommendation is not known. Thus this study described the use of specific services and the time spent in therapeutic activities by young children with ASD according to patient, family, and system characteristics.

METHODS

Study Design and Participants

A retrospective observational design was used to analyze deidentified data received from 19 current or former sites of the Autism Speaks Autism Treatment Network (ATN) and the Autism Intervention Network on Physical Health (AIR-P). The ATN/AIR-P registry sites are a network of multidisciplinary clinics providing diagnostic and treatment services to children with ASD across North America (22). Data were obtained from March 2008 to December 2013. All ATN/AIR-P sites are located in urban areas and are associated mostly with university medical centers. Children who met *DSM-IV* criteria for ASD and were treated at these centers were invited to participate in the registry and potential future studies upon their consent. In addition to a confirmed ASD diagnosis, registry inclusion criteria included age less than one year to 18 years, a plan for ongoing care at the ATN site, and parents who communicated in English. This study was deemed not to be human subjects research by the University of Arkansas for Medical Sciences Institutional Review Board.

This study used data from the baseline visit to the ATN/AIR-P registry site. The ATN/AIR-P administered a survey that asked parents to report information on whether their child received any of eight behavioral or educational interventions (hereafter referred to as services), including speech therapy; occupational therapy; physical therapy; social skills training; developmental, individual differences, relationship-based approach (DIR)/floor time; behavioral therapy (that is, applied behavioral analysis, Lovaas therapy, and discrete trial training); verbal behavior therapy; and other behavioral interventions. We further grouped the last three services (that is, excluding speech therapy, occupational therapy, physical therapy, and social skills training) as “any behavioral services.” These services were selected on the basis of evidence that supports improvement in child outcomes (11,23–25). Parents who reported use of any of the services were also asked to report the number of hours per week in the past month the child received each service. We limited the sample to children under age six to increase homogeneity, because including older children would have increased the probability of including children who were being seen for the first time for reasons other than to obtain a diagnosis or to begin receiving services. We then further

classified children into two groups: under age three (toddlers) and age three to less than six (preschoolers). The total number of hours children received services per week was calculated by summing hours per week for all services. Children with missing data on whether they received any services were excluded.

Measures

Clinical and quality-of-life measures. A number of clinical measures were used to determine whether service use was related to the severity of the condition, problem behaviors, or other aspects of the child’s quality of life. The Autism Diagnostic Observation Schedule (ADOS) measures ASD severity with relative independence from the child’s age and IQ (26). ADOS severity scores range from 1 to 10, with higher scores representing more severe ASD (27). The Child Behavior Checklist (CBCL) measures externalizing and internalizing behavior problems (28), with higher scores representing more behavioral problems. The Vineland-II Adaptive Behavior Scales (Vineland-II) composite score was reported in this study, with higher scores reflecting better adaptive functioning (29).

Three measures of cognitive ability (IQ) were used, including the fifth edition of the Stanford-Binet Intelligence Scales (30), the Mullen Scales (31), and the Bayley Scales (32). A cutoff of 70 was used for all measures on the basis of standard accepted ranges of cognitive disability (33). The 23-item Pediatric Quality of Life Inventory was used to measure health-related quality of life of children with ASD (34); higher scores represent better quality. All scores were categorized into three groups by using the mean and SD of the sample to identify poor, moderate, and good scores based on their respective distributions.

Other variables. Demographic and clinical characteristics of children, including age, gender, race (white or nonwhite), previous ASD diagnosis (yes or no) before the baseline visit, current ASD diagnosis, and health insurance status were collected at the baseline visit and were included in the study. Maternal education level was also determined and included in the study.

Statistical Analysis

Descriptive statistics for baseline demographic characteristics and instrument scores for all children with ASD were provided and categorized by whether the child received at least one service and whether the child received any behavioral services. Chi-square tests were used to examine the difference in demographic and clinical characteristics between the group of children who received and those who did not receive any services. We found that the total number of hours of services received was not normally distributed. [A figure in an online supplement to this article shows the distribution at baseline.] Therefore, the Wilcoxon rank-sum or Kruskal-Wallis tests were applied to test for significance.

The percentage of missing data in the final data set ranged from .04% (gender) to 26% (IQ). We did not observe a

TABLE 1. Characteristics of 2,804 children under age 6 with a diagnosis of autism spectrum disorder (ASD) at registry enrollment

Characteristic	N with data	N	%
Age (M±SD)	2,804	3.8±1.1	
Male	2,803	2,331	83
White race	2,466	2,075	84
ADOS severity score (M±SD) ^a	2,309	7.0±1.8	
Prior ASD diagnosis	2,802	908	27
Duration of prior ASD diagnosis prior to registry enrollment (M±SD years)	908	1.0±1.0	
ASD diagnosis	2,625		
Autism		2,053	78
Asperger's		79	3
Pervasive developmental disorder, not otherwise specified		493	19
Cognitive ability (M±SD score) ^b	2,804	70.3±23.9	
>70		1,158	41
≤70		930	33
Missing		716	26
Maternal education level	2,771		
High school diploma, GED, or lower		566	20
Some college		849	31
Bachelor's degree		747	27
Graduate degree		609	22
Insurance status	2,316		
None		56	2
Private only		1,033	45
Public only		1,055	46
Both private and public		172	7
CBCL total T score (M±SD) ^c	2,568	63.8±11.5	
PedsQL total score (M±SD) ^d	2,600	69.1±14.8	
Vineland-II composite score (M±SD) ^e	2,405	72.1±12.0	

^a Autism Diagnostic Observation Schedule. Possible scores range from 1 to 10, with higher scores representing greater severity.

^b Overall IQ. Available scores from Stanford-Binet (full scale and abbreviated), Mullen (ELC standard score), and Bayley (cognitive composite) were used.

^c Child Behavior Checklist. Possible scores range from 0 to 100, with higher scores indicating more behavioral problems.

^d Pediatric Quality of Life Inventory. Possible scores range from 0 to 100, with higher scores indicating better quality of life.

^e Vineland-II Adaptive Behavior Scales. Possible scores range from <20 to 137, with higher scores indicating better adaptive behavioral skills.

specific pattern of missingness. Therefore, we assumed that data were missing at random (MAR). Under the MAR assumption, other variables in the data set can be used to predict missingness on a given variable (35). We imputed all missing data except for IQ by using the multiple imputation approach. For the IQ variable, we included a dummy variable for missing IQ as a category along with whether or not the child was below the cognitive ability cutoff of 70. Multiple imputation by chained equations was selected in order to use a separate conditional distribution for each imputed variable, with 80 imputation sets.

Two dependent variables (whether the child received any behavioral services and total number of hours per week of services used) were analyzed separately by using logistic regression and generalized linear models (GLM), respectively. The GLM models do not require a

transformation of the dependent variable and can accommodate heteroscedasticity (36). A Poisson family with a logarithmic link function was selected for the GLMs in all analyses on the basis of a modified Park test. Three models were built that first included only child demographic characteristics (age, gender, and race), previous ASD diagnosis, health insurance status of the child, and maternal education level. Model 1 added the child's IQ and ADOS severity score to the base model, and model 2 added the child's CBCL total T score and the Vineland-II composite score to model 1. ATN/AIR-P site and year of the baseline visit were included in all the models as fixed effects. Variation in parent-reported hours of services received for toddlers and preschoolers across ATN/AIR-P sites were predicted from the GLM base model by using only complete data. All statistical analyses were conducted in Stata/SE 14.2.

RESULTS

Table 1 presents data on demographic and clinical characteristics of 2,804 children registered in the ATN/AIR-P at baseline who had information on services; 2,047 (73%) were in the preschooler group. The mean age of the entire sample was 3.8 years. Most were male (N=2,331, 83%) and of white race (N=2,075, 84%). In the sample, 2,053 (78%) had a diagnosis of autism, and a quarter (N=908, 32%) had been diagnosed as having ASD prior to the baseline visit at the ATN/AIR-P registry. In the sample, 930 (33%) had cognitive ability score ≤70; the mean ADOS severity score for the sample was 7.0.

Table 2 presents parent-reported baseline data on services received, along with the mean number of hours of services received per week. Among all children, 2,240 (79%) received at least one service. Speech therapy and occupational therapy were the most frequent services received (N=1,879, 67%, and N=1,402, 50%, respectively). Only 772 (28%) of children received any behavioral services. On average, the highest mean number of hours per week was for the group who reported receiving any behavioral services (mean=12.7).

Table 3 provides information on the proportion of children who received any services and any behavioral services and the number of hours per week of services received, categorized by child characteristic. The proportion of children who received at least one service was higher among white children than among nonwhite children (81% versus

71%, $p < .001$), and white children also spent more hours per week in services (7.7 versus 6.4, $p = .019$). Among children with a previous ASD diagnosis at the baseline visit, 90% received at least one service, compared with 74% of those who did not have a previous diagnosis ($p < .001$), and the group with a previous diagnosis spent more hours per week in services (10.1 versus 5.9, $p < .001$). The education level of the mother and the child's insurance status were associated with receipt of any services; children of mothers with a higher education level were more likely to receive any services.

As shown in Table 3, the proportion of children receiving any behavioral services was larger among toddlers than among preschoolers (33% versus 26%, $p < .001$), but the average number of hours received per week was higher in the preschooler group (10.6 versus 6.4, $p < .001$). A greater proportion of white children than non-white children used any behavioral services (30% versus 22%, $p = .002$); however, no difference was found in the average hours received per week. The proportion of children using any behavioral services was substantially larger among children who had a prior ASD diagnosis at the baseline visit, compared with those who did not (42% versus 21%, $p < .001$). Most children in the sample (62%) received fewer than ten hours per week of any behavioral services. Only 10% received ≥ 25 hours per week of behavioral services.

Table 4 presents findings from three logistic regression models that assessed factors associated with the probability of reported use of any behavioral services at the baseline visit. Across all three models, higher socioeconomic status (as measured by maternal education level) was associated with a greater likelihood of receiving behavioral services. Results from model 2 showed that being white was associated with a greater likelihood (odds ratio [OR]=1.51) of use of any behavioral services; higher maternal education was associated with a doubling of the odds of receiving behavioral services. Of note, adding the child's IQ to the model indicated that those with a low IQ were less likely to receive behavioral services (model 1, OR=.70; model 2, OR=.71). The time dummy variables indicated a consistent trend toward greater use of behavioral services over the study period, with children in the later years of the study being more than twice as likely to have received behavioral services prior to their baseline visit.

Table 5 provides findings from three GLM regressions describing factors associated with time spent in any services, including behavioral services. The associations with demographic characteristics were similar to those for use of behavioral services. Being male, white, having a prior ASD diagnosis, and maternal education were all associated with spending more time in services. No effect of insurance was noted. Low IQ and missing IQ were associated with less time spent in services, and higher

TABLE 2. Parent-reported services received by 2,804 children under age 6 with a diagnosis of autism spectrum disorder at registry enrollment

Service	N	%	Hours per week ^a	
			M	SD
Speech therapy	1,879	67	2.1	3.9
Occupational therapy	1,402	50	1.7	3.1
Any behavioral therapy ^b	785	28	12.7	11.5
Physical therapy	421	15	1.5	3.5
Social skills training	336	12	4.6	5.7
Developmental, individual differences, relationship-based approach/floor time	196	7	4.1	6.1

^a Among children receiving the service

^b Includes behavioral therapy (applied behavior analysis, Lovaas therapy, and discrete trial training), verbal behavior training, and other behavioral interventions

ADOS severity scores were associated with more time spent in services.

The predicted average total number of service hours per week across the ATN/AIR-P sites was from the base GLM model [see figure in online supplement]. The predicted mean $\pm$ SD hours per week of service use for children with ASD across the 18 sites ranged from 3.1 ± 1.0 to 9.5 ± 2.1 .

DISCUSSION

Prospects for children with autism improved greatly following the discovery that behavioral interventions could improve outcomes. As Thompson (37) noted, 30 years ago there were few treatments for children with ASD, resulting in the vast majority of children being placed in classrooms for children with severe disabilities and then in large public institutions, where they remained for the rest of their lives. Now, half of children with ASD who receive early and intensive behavioral interventions participate in regular classrooms alongside their peers, and the others are trained for vocational goals. The discovery that behavioral interventions could transform the lives of children and families affected by ASD led to a push for better methods to identify children with ASD and then initiate early intensive treatment (11,23). Experts now recommend at least 25 hours per week of applied behavioral analysis (ABA) for children with deficits in multiple areas and more limited or focused ABA treatment for children with milder symptoms (10). Unfortunately, this study and others found that only a small percentage of young children with ASD meet this recommendation.

In this study, 20% of children with ASD did not receive any evidence-based services prior to their baseline visit, even though 22% of the children in this category had cognitive ability scores below the cutoff for intellectual disability. Indeed, only 28% of children received any behavioral services prior to their baseline visit, and having intellectual disability was associated with much lower use of behavioral services. In a sensitivity analysis, children with worse ADOS severity scores (scores of 8–10) and worse Vineland-II composite scores were no more likely to receive any behavioral services prior to the baseline visit. Autism severity scores of children

TABLE 3. Use of services by 2,804 children under age 6 with a diagnosis of autism spectrum disorder (ASD) at registry enrollment, by characteristic at enrollment

Characteristic	Total N	Any service			Hours per week ^a			Any behavioral service			Hours per week ^a		
		N	%	p ^b	M	SD	p ^c	N	%	p ^b	M	SD	p ^c
Age	2,804			.005			.003			<.001			<.001
<3 (toddlers)	757	620	82		6.1	7.7		247	33		6.4	7.3	
3 to <6 (preschoolers)	2,047	1,473	72		8.0	10.1		525	26		10.6	10.3	
Gender	2,803			ns			ns			ns			ns
Female	472	359	76		7.3	11.3		124	26		8.5	9.0	
Male	2,331	1,865	80		7.5	9.3		647	28		9.4	9.8	
Race	2,466			<.001			.019			.002			ns
Nonwhite	391	278	71		6.4	8.8		86	22		9.1	9.5	
White	2,075	1,671	81		7.7	10.4		620	30		9.2	9.6	
ADOS severity score ^d	2,309			ns			ns			ns			.011
1–4	221	164	74		5.8	8.0		44	20		9.1	9.5	
5–7	1,251	976	78		7.0	9.7		305	24		8.5	8.7	
8–10	837	661	79		8.3	11.3		228	27		11.4	11.1	
Prior ASD diagnosis	2,802			<.001			<.001			<.001			<.001
No	1,894	1,402	74		5.9	8.9		388	21		8.2	9.2	
Yes	908	817	90		10.1	11.4		382	42		10.4	10.0	
ASD diagnosis	2,625			.012			.007			ns			ns
Autism	2,053	1,654	80		7.7	7.7		586	22		6.3	7.5	
Asperger's	79	52	66		4.8	7.1		17	29		9.4	9.7	
Pervasive developmental disorder, not otherwise specified	793	388	78		6.7	9.4		120	24		8.2	8.3	
Cognitive ability score ^e	2,804			ns			ns			ns			ns
>70	1,158	926	80		7.7	10.1		342	30		9.2	9.3	
≤70	930	725	78		7.1	9.7		235	25		8.7	8.7	
Missing	716	558	78		7.5	10.7		195	27		10.0	11.2	
Maternal education level	2,771			<.001			<.001			<.001			.017
High school diploma, GED, or less	566	405	71		5.9	8.4		108	19		7.3	9.0	
Some college	849	673	79		7.0	9.9		197	23		8.9	9.1	
Bachelor's degree	747	633	84		8.1	10.9		249	33		9.8	9.9	
Graduate degree	609	499	81		8.5	10.6		205	34		10.3	10.3	
Insurance status	2,316			<.001			.012			<.001			ns
None	56	46	82		7.1	8.6		13	23		12.7	11.0	
Private only	1,033	847	82		7.9	10.8		300	29		10.1	10.7	
Public only	1,055	812	77		6.9	9.8		272	26		8.1	8.6	
Both private and public	172	157	91		7.9	8.8		79	46		9.5	9.4	
Hours of services per week ^a	2,212						772						
<10		1,706	77					481	62				
10–14.9		159	7					101	13				
15–19.9		114	5					67	9				
20–24.9		67	3					48	6				
≥25		166	8					75	10				
CBCL total T score ^f	2,568			.036			ns			ns			ns
Mild	443	348	77		6.5	8.1		111	25		7.9	7.4	
Moderate	1,717	1,403	81		7.8	10.6		490	29		10.1	10.4	
Severe	408	311	76		7.4	9.7		116	28		7.6	7.9	
PedsQL total score ^g	2,587			ns			ns			.020			ns
Poor	405	328	81		8.7	12.2		126	31		8.9	10.1	
Moderate	1,760	1,408	80		7.5	10.1		500	28		9.4	9.8	
Good	422	321	76		7.0	8.9		96	23		10.1	8.7	

continued

TABLE 3, continued

Characteristic	Total N	Any service			Hours per week ^a			Any behavioral service			Hours per week ^a		
		N	%	p ^b	M	SD	p ^c	N	%	p ^b	M	SD	p ^c
Vineland-II composite score ^h	2,403			.043			ns			ns			ns
Poor	1,131	916	81		7.6	10.9		306	27		8.9	9.8	
Moderate	957	746	78		7.2	9.1		269	28		8.7	8.5	
Good	315	236	75		6.7	9.0		81	26		9.5	9.1	

^a Among those who used the indicated service^b Calculated with the chi-square test^c Calculated with the Wilcoxon rank-sum test or Kruskal-Wallis test^d Autism Diagnostic Observation Schedule. Possible scores range from 1 to 10, with higher scores representing greater severity.^e Overall IQ. Available scores from Stanford-Binet (full scale and abbreviated), Mullen (ELC standard score), and Bayley (cognitive composite) were used.^f Child Behavior Checklist^g Pediatric Quality of Life Inventory^h Vineland-II Adaptive Behavior Scales

who had not received behavioral services were similar to those of children who had received any services (data not shown), suggesting that a substantial number of children do not receive necessary services early in their life course. The most frequent intervention reported in our study was

speech therapy, which is consistent with the literature (38), followed by occupational therapy, and any behavioral services.

The study contributes to the literature by demonstrating that socioeconomic characteristics and system factors

TABLE 4. Association between demographic and clinical characteristics of 2,766 children with a diagnosis of autism spectrum disorder (ASD) and probability of receiving any behavioral services at registry enrollment^a

Variable	Base model			Model 1			Model 2		
	OR	95% CI	p	OR	95% CI	p	OR	95% CI	p
Age 3 to <6 years (reference: <3 years)	.69	.56–.85	.001	.74	.59–.92	.006	.71	.57–.88	.002
Male (reference: female)	1.12	.88–1.44	ns	1.13	.88–1.45	ns	1.16	.90–1.49	ns
White (reference: nonwhite)	1.45	1.08–1.95	.013	1.51	1.12–2.03	.007	1.51	1.12–2.04	.007
Previous ASD diagnosis (reference: no)	2.41	1.90–3.05	<.001	2.39	1.89–3.03	<.001	2.35	1.86–2.99	<.001
Maternal education level (reference: high school diploma, GED, or less)									
Some college	1.14	.85–1.54	ns	1.18	.87–1.58	ns	1.20	.89–1.62	ns
Bachelor's degree	1.81	1.34–2.46	<.001	1.88	1.39–2.56	<.001	1.98	1.45–2.71	<.001
Graduate degree	1.78	1.30–2.43	<.001	1.88	1.37–2.58	<.001	1.98	1.43–2.75	<.001
Insurance status (reference: none)									
Private only	1.75	.92–3.50	ns	1.69	.87–3.30	ns	1.71	.88–3.32	ns
Public only	1.58	.82–3.04	ns	1.51	.79–2.89	ns	1.46	.76–2.81	ns
Both private and public insurance	2.70	1.31–5.55	.007	2.59	1.27–5.31	.009	2.55	1.24–5.23	.011
IQ (reference: >70) ^b									
≤70				.70	.55–.88	.003	.71	.54–.92	.010
Missing				.89	.70–1.13	ns	.89	.70–1.14	ns
ADOS severity score				1.06	1.00–1.12	ns	1.06	1.00–1.12	ns
CBCL total T score							1.01	1.00–1.02	ns
PedsQL total score ^c							1.00	.99–1.01	ns
Vineland-II composite score							1.00	.99–1.01	ns
Year (reference: 2009)									
2010	.71	.49–1.01	ns	.71	.49–1.02	ns	.71	.50–1.03	ns
2011	1.33	.92–1.91	ns	1.33	.92–1.92	ns	1.32	.91–1.90	ns
2012	2.16	1.51–3.10	<.001	2.14	1.49–3.09	<.001	2.16	1.50–3.12	<.001
2013	2.74	1.91–3.93	<.001	2.71	1.88–3.90	<.001	2.68	1.86–3.87	<.001
Constant	.06	.02–.13	<.001	.04	.02–.11	<.001	.04	.01–.20	<.001

^a Behavioral services include behavioral therapy (that is, applied behavioral analysis, Lovaas therapy, and discrete trial training), verbal behavior therapy, and other behavioral interventions. ORs are based on the logistic regression with robust standard errors, controlled by site. Year 2008 was omitted because of the small sample size (N=38). Multiple imputation by chained equations was used to impute missing data for gender, race, previous ASD diagnosis, maternal education level, Autism Diagnostic Observation Schedule (ADOS) severity score, Child Behavior Checklist (CBCL) total T score, and Vineland-II Adaptive Behavior Scales (Vineland-II) composite score with 80 imputation sets. Area under the ROC curve values for base model, model 1, and model 2 are .764, .767, and .769, respectively.

^b Overall IQ. Available scores from Stanford-Binet (full scale and abbreviated), Mullen (ELC standard score), and Bayley (cognitive composite) were used.

^c Pediatric Quality of Life Inventory

TABLE 5. Coefficients from generalized linear models for associations between characteristics and hours of services received among 2,765 children under age 6 with a diagnosis of autism spectrum disorder (ASD) at registry enrollment^a

Variable	Base model			Model 1			Model 2		
	Coeff.	SE	p	Coeff.	SE	p	Coeff.	SE	p
Age 3 to <6 years (reference: <3 years)	.18	.02	<.001	.23	.02	<.001	.21	.02	<.001
Male (reference: female)	.05	.02	.037	.05	.02	.012	.06	.02	.007
White (reference: nonwhite)	.18	.04	<.001	.20	.04	<.001	.21	.04	<.001
Previous ASD diagnosis (reference: no)	.53	.02	<.001	.50	.02	<.001	.49	.02	<.001
Maternal education level (reference: high school diploma, GED, or less)									
Some college	.23	.03	<.001	.25	.03	<.001	.26	.03	<.001
Bachelor's degree	.36	.03	<.001	.39	.03	<.001	.40	.03	<.001
Graduate degree	.38	.03	<.001	.42	.03	<.001	.43	.03	<.001
Insurance status (reference: none)									
Private only	-.03	.10	ns	-.06	.10	ns	-.07	.10	ns
Public only	-.08	.10	ns	-.11	.10	ns	-.14	.10	ns
Both private and public	-.03	.10	ns	-.07	.11	ns	-.12	.11	ns
IQ (reference: >70) ^b									
≤70				-.28	.02	<.001	-.20	.03	<.001
Missing				-.10	.02	<.001	-.08	.02	<.001
ADOS severity score				.05	.01	<.001	.05	.01	<.001
CBCL total T score							-.003	.001	.034
PedsQL total score ^c							-.003	.001	.001
Vineland-II composite score							-.007	.002	<.001
Year (reference: 2009)									
2010	-.06	.03	.044	-.05	.03	ns	-.06	.03	.039
2011	-.04	.03	ns	.05	.03	ns	-.07	.03	.036
2012	.03	.03	ns	.005	.03	ns	-.005	.03	ns
2013	.17	.03	<.001	.15	.03	<.001	.14	.03	<.001
Constant	1.03	.11	<.001	.71	.13	<.001	1.70	.25	<.001

^a Multiple imputation by chained equations was used to impute missing data for gender, race, previous ASD diagnosis, maternal education level, Autism Diagnostic Observation Schedule (ADOS) severity score, Child Behavior Checklist (CBCL) total T score, and Vineland-II Adaptive Behavior Scales (Vineland-II) composite score with 80 imputation sets. Estimates with robust standard errors (SE) are based on the Poisson family with a logarithmic link, controlled by site and year.

^b Overall IQ. Available scores from Stanford-Binet (full scale and abbreviated), Mullen (ELC standard score), and Bayley (cognitive composite) were used.

^c Pediatric Quality of Life Inventory

contribute to differences in the use of services in a larger sample than in previous studies and across various geographic locations. The differences in use could be explained by differences in clinical characteristics of the child with ASD. More research is needed to better understand why children with intellectual disability or with more behavioral problems appeared to be at risk of not receiving early services.

The study had limitations. First, the analysis was built on parental report of service use at the baseline visit for a sample of children diagnosed at academic centers specializing in the diagnosis and treatment of ASD. Some of the variation in use of interventions may have been due to systematic differences in the ability to recall service use. The main instrument used to capture use of services lacks formal testing for psychometric properties as is typical of resource use measurement tools (39). One recommendation is for centers that document utilization information to adopt a validated instrument to allow comparison across study centers and to identify strategies to ensure that areas with low resource utilization are included in research studies. Research on ASD using registries provides a number of strengths, but limitations are present and should be acknowledged (40).

Second, it is likely that many children initiated services following the baseline visit and that an analysis of service use in a later period would have found a higher proportion of children receiving services. In addition, the reason for variation in service use across treatment centers is not clear. Differences in use of interventions at a given treatment center reflect demographic and health system factors in the region, referral patterns, and other unobserved characteristics. Understanding system-level factors that contribute to variation in the use of services is another area for future research.

Finally, because of the high rate of missing data associated with some factors, our regression estimates relied on imputation procedures. We estimated models both with and without imputation, and the findings were qualitatively similar. Socio-economic and clinical factors associated with service use were consistently identified irrespective of the use of imputation procedures or the specification of the regression model.

CONCLUSIONS

The use of early interventions for children with ASD was found to vary according to child, family, and system characteristics. Given the evidence on use of behavioral and other services to

address the core symptoms and myriad comorbid conditions associated with ASD, increased efforts to initiate early interventions appear warranted. These efforts need to target low-income, nonwhite children as well as children identified with intellectual disability.

AUTHOR AND ARTICLE INFORMATION

Dr. Payakachat is with the Department of Pharmacy Practice and Dr. Tilford is with the Department of Health Policy and Management, University of Arkansas for Medical Sciences, Little Rock. Dr. Kuhlthau is with the Department of Pediatrics, Harvard Medical School, and the Division of General Academic Pediatrics, Massachusetts General Hospital, Boston. Send correspondence to Dr. Payakachat (e-mail: npayakachat@uams.edu). Initial findings were presented at the National Institute of Mental Health Conference on Mental Health Services Research, Bethesda, Maryland, August 1–3, 2016, and at AcademyHealth, Minneapolis, June 14–16, 2015.

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Dr. Payakachat reports service as a paid consultant to Roche Ltd., service as a consultant to CBPartners, and ownership of stock in Pfizer. Dr. Tilford reports service as a paid consultant to Roche Ltd. Dr. Kuhlthau reports service as a paid consultant to Roche Ltd. and stock ownership in Johnson and Johnson.

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First-Person Accounts Invited for Column

Patients, family members, and mental health professionals are invited to submit first-person accounts of experiences with mental illness and treatment for the Personal Accounts column in *Psychiatric Services*. Maximum length is 1,600 words.

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