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## Community-based service use in preschool children with autism spectrum disorder and associations with insurance status



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### ABSTRACT

**Background:** ASD-related services can improve outcomes for children, but less is known about service outside of school settings during preschool age. We aimed to describe amount and category of community-based service use among 3–5-year-old children with ASD and examine differences by health insurance.

**Methods:** We used cross-sectional data on 792 children with ASD diagnoses in the Study to Explore Early Development, a community-based study of neurodevelopment with enrollment between 2012–2016. Mothers reported current child service use and insurance status at study entry. We used log-Poisson and logistic regression to compare service use by insurance group.

**Results:** Nearly 40% of children were not receiving community-based services at study entry. Children with public insurance had fewer total services than children with private or both insurances. After adjustment for sociodemographic confounders, insurance status was not associated with amount of different categories of community-based services. However, children with public insurance alone were least likely to receive community-based behavioral therapy and most likely to receive psychotropic medication compared to other insurances.

**Conclusion:** Many preschool-aged children do not receive community-based services, with receipt of some service types associated with insurance type. Increasing access and availability for evidence-based service, especially for beneficiaries of public insurance, may improve service use and outcomes.

## 1. Introduction

The most recent Autism and Developmental Disabilities Monitoring Network estimate of ASD prevalence in 8-year-old children in

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sites across the US is 1 in 59, with median age of diagnosis at 52 months (Baio et al., 2018). With increasing identification of ASD at younger ages (Baio et al., 2018) it is crucial that appropriate medical and behavioral-based services, treatments, and therapies (hereafter referred to collectively as ‘services’) are available and accessible (Dawson & Burner, 2011; Zablotsky et al., 2015). Such early identification and referral to services have been shown to improve outcomes and reduce expenditures for families and health systems (Horlin, Falkmer, Parsons, Albrecht, & Falkmer, 2014; Leigh, Grosse, Cassady, Melnikow, & Hertz-Picciotto, 2016). A particularly crucial time for intervention is the period before the age of 5 years where a child develops many social and communication skills (Koegel, Koegel, Ashbaugh, & Bradshaw, 2014; Zwaigenbaum et al., 2015). Providing adequate and timely services to preschool children with ASD has been shown to have positive impacts on both short and long-term outcomes (Koegel et al., 2014).

Most services for children with ASD aim to improve adaptive functioning, language, and social skills, as well as reduce challenging behaviors (Harrington & Allen, 2014). Behavioral therapy is a common intervention for children with ASD and is based on identifying the antecedents and consequences of specific behaviors to modify environmental conditions according to the needs of the child (Kasari, 2015). Behavioral therapy, which includes applied behavior analysis, is considered among “best practice” guidelines for treating ASD symptoms in young children. Behavioral therapy covers a range of approaches but there still is uncertainty about optimal designs, intensity, and approach (Reichow, Hume, Barton, & Boyd, 2018; Zwaigenbaum et al., 2015). Speech therapy is a common service for children with ASD, especially in school settings (O’Hare & Bremner, 2016), as language delays are among the first symptoms noted by parents of children with ASD (Herlihy, Knoch, Vibert, & Fein, 2015). Physical therapy (PT) and occupational therapy (OT) are used to address common physical and adaptive challenges associated with ASD, as well as sensory over- or under-response (Hebert, Kehayia, Prelock, Wood-Dauphinee, & Snider, 2014; Semansky, Xie, Lawer, & Mandell, 2013). Social skills training focuses on social deficits and can include peer-mediated interventions or stories that provide visual cues to help navigate unfamiliar social interactions (Bohlander, Orlich, & Varley, 2012). Medications are often prescribed to treat certain symptoms associated with the ASD phenotype, such as inattention, and hyperactivity (Baribeau & Anagnostou, 2014). In addition to standard care, caregivers commonly initiate complementary health approaches (CHA) for their children with ASD in an attempt to alleviate symptoms (Barrett et al., 2015; Levy & Hyman, 2015; Rubenstein et al., 2018). While we present services by type, it is important to note that there are myriad of variants in approach, intensity, duration, and setting for each type of service (Lord, Elsabbagh, Baird, & Veenstra-Vanderweele, 2018).

Research finds that children with ASD often do not get the level of services that families desire. In the 2009–2010 National Survey of Children with Special Health Care Needs, 24.4% of children < 18 years old with ASD had unmet service needs (Benevides, Carretta, Ivey, & Lane, 2017). In that same study, caregivers reported the most common reason for difficulty in obtaining services were cost, health plan problems, and lack of school resources (Benevides et al., 2017). Using data from the 2011–2014 National Health Interview Study, Lindly, Zuckerman, and Kuhlthau (2018) found that 15.8% of children 2–17 with ASD had a delay accessing needed care and 14.5% did not receive needed care because of cost. During preschool age, many children receive services but behavioral based therapies are less common (Payakachat, Tilford, & Kuhlthau, 2018). Appropriate services, especially during the early childhood period, are crucial to improve short and long-term outcomes (Koegel et al., 2014). Better understanding of determinants and associated factors for why these gaps in care exist will enable for better service allocation and care for preschool-age children with ASD.

The unmet service need is partially attributable to a lack of access to community-based care (Lindly et al., 2018). Children who meet criteria for special education services are required by law to receive individualized services for ASD (Individuals with Disabilities Education Improvement Act of 2004, 2004); however, care is often needed outside the school setting. Often, community-based services take place at specialty clinics or programs like Head Start and have a cost- whether out-of-pocket or to the government or insurance providers (Candon et al., 2018). In the context of health insurance, a child may receive public coverage because a family meets certain income requirements or through a special waiver program. A child may be enrolled in private insurance because a family buys into a plan or a parent’s employer provides coverage (Lindly et al., 2018). Insurance status is an important indicator for socioeconomic status and may highlight disparity in health care utilization (Lindly et al., 2018). Over the last ten years, many states have enacted insurance mandated laws impacting how private insurance providers cover children with ASD (Barry et al., 2017; Douglas, Benevides, & Carretta, 2017). Governmental programs like the Children’s Health Insurance Program (CHIP) and Medicaid are required to provide certain ASD-related coverage and are available to the public if they meet certain eligibilities (Barry et al., 2017; Douglas et al., 2017). In addition to public and private programs, state-based Medicaid Home and Community Based Services (HCBS) waivers provide services to eligible children with ASD or developmental disabilities regardless of family income (Cidav, Marcus, & Mandell, 2014; Leslie et al., 2017; Vohra, Madhavan, & Sambamoorthi, 2017; Wang, Mandell, Lawer, Cidav, & Leslie, 2013). States differ in how children are eligible for the waivers, how many receive the waiver, and what services the waiver covers (Velott et al., 2016). Waiver programs allow public insurance money to supplement existing public or private insurance for ASD-related expenditures.

Although insurance programs and laws have aimed to expand care for children with ASD, many programs and service providers are burdened with long waitlists and limited funds and many children do not get the services they need (Miller, Merryman, Eskow, & Chasson, 2016). Insurance type likely impacts access; one study found that children with ASD enrolled in Medicaid were more likely to have visits to OTs, PTs, and behavioral therapists compared to children on private insurance (Wang et al., 2013). Children with ASD-related HCBS waivers were more likely to have outpatient visits and less likely to have inpatient visits and long-term treatment than children without HCBS waivers (Cidav et al., 2014). The community-based service a child receives is affected by the insurance policies in place at a state (i.e. HCBS waivers, insurance mandates) and state and national level (i.e. Medicaid, CHIP) as well as an individual family’s ability to spend out-of-pocket and familiarity with service systems (Candon et al., 2018; Miller et al., 2016; Thomas, Parish, & Williams, 2014).

Appropriate services for preschool children with ASD are crucial for development; yet, there may be differences in service use due to socioeconomic factors. The objective of the present study was to describe community-based service use at a critical developmental age (3–5 years) among children with a diagnosis of ASD using data from the Study to Explore Early Development (SEED). Additionally, we examined differences by insurance status (public insurance, private insurance, or combined insurance [i.e. private insurance and HCBS waiver]). Lastly, we evaluated whether the association between insurance status and service use differed by the child's ASD symptom severity. We hypothesized that we would see a proportion of preschool age children who did not receive community-based service and that proportion would be associated with insurance type.

## 2. Methods

### 2.1. Design and participant ascertainment

We used data from SEED; a community-based multi-site case-control study of ASD etiology and phenotype in children 30–68 months old (Schendel et al., 2012). Six sites participated in the study (California, Colorado, Georgia, Maryland, North Carolina and Pennsylvania). We used data from families who completed the study between 2012 and 2016. Each site's institutional review board and the review board at the Centers for Disease Control and Prevention approved the SEED protocol. Additional SEED information can be found in Schendel et al. (2012).

Three groups of children and their mothers were invited to participate in this study: children with ASD, children with other (non-ASD) developmental disabilities, and children from the general population. Children were identified from healthcare providers and education agencies that diagnosed or served children with disabilities and from random sampling of birth certificates in each study site's catchment area (selected counties in a state with > 35,000 live births per year). This present study was concerned with services used by children with ASD, thus we limited our analysis to children with ASD diagnosis prior to study enrollment. SEED methodology was designed to be able to identify children with no past diagnosis of ASD, but those children would not have had opportunity for ASD-related service. Past diagnosis was ascertained by asking the mother about her child's diagnostic history and/or by reviewing diagnostic codes in a child's medical record. We excluded 12.7% of children who met SEED criteria for ASD case status but did not have an ASD diagnosis prior to enrollment and would not have been eligible for ASD-related services prior to study entry (Wiggins et al., 2015). A group of children with prior ASD diagnosis but did not meet SEED ASD criteria during the research evaluation were included in this analysis since they could have received ASD-specific services.

### 2.2. Current service use

As part of SEED data collection, the mother completed a questionnaire developed by SEED investigators aimed at capturing information on ASD-related service use. Mothers filled out a questionnaire that asked 'Has your child ever used any of the following services or therapies' followed by a list of potential services. For each service reported, the mother was asked whether the child was still receiving this service and whether the service took place out-of-school. We examined services that were explicitly prompted: speech therapy, OT, behavior therapy, respite care, social skills training, PT, CHA, and 'other' (see supplement 1a). Specific CHA therapies that required seeing a service provider (chelation therapy, chiropractic care, hyperbaric oxygen therapy, and immune treatments) were analyzed as a group. We ascertained medication use from the answer to the following question: 'Is your child currently on any prescription medications for ASD-related symptoms or behaviors, including antidepressants/antianxiety or anti-obsessive-compulsive medications, atypical antipsychotics, medications to treat seizures or stabilize mood, and non-stimulants used to treat hyperactivity?'

### 2.3. Insurance status

SEED collected data on child insurance status through a child health history form completed by the mother. The form included the question 'Does your child currently have any of the following types of health insurance coverage: 1) Private insurance including HMOs (provided through a job or private insurance); 2) Government plans (e.g. Medicaid); 3) Other type of insurance (and if yes, specify); 4) Child is currently uninsured.' Respondents could indicate more than one type of insurance coverage. The text field for the 'other' group was assessed to determine whether any listed responses would fit in the private or public category (text field responses available in supplement 1b). We coded insurance status into four categories for analysis: 1) private insurance alone, 2) public insurance alone, 3) combined insurance (both private and public insurance), 4) uninsured. Participants were not asked about the specific plan in which the child was currently enrolled or prior history of health insurance enrollment. We did not include uninsured children in our analyses due to small sample size (N = 11, 1.4%).

### 2.4. Other covariates

The Social Communication Questionnaire (Rutter, Bailey, & Lord, 2003) was administered as a preliminary screener in SEED and we dichotomized whether the child met criteria (cutoff score  $\leq 11$  to improve identification in children under 4 (Wiggins, Bakeman, Adamson, & Robins, 2007)). We used demographic data from the SEED maternal interview to examine characteristics of the sample. Mothers were asked their education (categorized as < high school degree, high school degree, some college, > = bachelor's degree), race (white, black, Asian, other), and family income in the past 12 months (< \$30,000, \$30,000-\$90,000, > \$90,000). Mothers were

also asked how many children were living in the household at the time of the interview and we categorized that into 1, 2, or 3+ children. ASD severity was derived from the Autism Diagnostic Observation Schedule (Lord et al., 2000), which children with past ASD diagnoses were administered as part of the SEED study protocol.

## 2.5. Analysis

We created binary indicators for each current service use (speech therapy, OT, behavior therapy, social skills training, respite care, PT, medication, CHA, and other). The cumulative types of different categories of service reflects the sum of these indicator variables. To evaluate associations between types of different categories of service and insurance status, we used log Poisson regression with study site as a random intercept. In our data, the mean amount of service types a child received was not statistically significantly different than the variance, supporting the use of a Poisson model. Having site as a random intercept allowed us to account for differences at the state level and variance between data collection across sites. In the adjusted models we controlled for confounders identified a priori based on a directed acyclic graph: maternal education, race, family income, number of children in the household, and child's year of birth. We selected these variables because of the association between socioeconomic status, insurance, and ASD related disparity. Additionally, including child's year of birth allowed us to account for child age and trend effects. As a sensitivity analysis, we evaluated differences when additionally incorporating school-based services, as identified using the same methodology used for community-based services. To examine the association between use of a specific service and insurance status, we ran logistic regression models for each service, controlling for previously mentioned covariates. We assessed whether the associations between insurance status and total types of services used, behavioral therapy, and medication use differed by ASD severity. Because of small sample size in the stratified model we re-parameterized race (white or not white) and education (no college, some or more college) to improve model convergence. Statistical significance is presented at an alpha = 0.05 level.

## 3. Results

### 3.1. Demographic characteristics

Our analytic sample consisted of 792 children with an ASD diagnosis prior to study enrollment (Table 1). At the time of data collection, 279 children (34.7%) were covered by public insurance alone, 406 (50.6%) had private insurance alone, and 107 (13.3%) had combined insurance. Less than half of mothers with children enrolled in public insurance alone were white whereas two-thirds of mothers with children on private insurance alone and three-quarters with combined insurance were white. More than half of the mothers with children on public insurance alone reported an income in the last 12 months < \$30,000 and of those with private insurance alone, approximately half earned  $\geq$  \$90,000.

### 3.2. Current service use

Approximately 60% of children received  $\geq 1$  community-based service (Table 2). Speech therapy and OT were the most common services for the overall sample and in each insurance group. Slightly less than half of children on public insurance alone received no community-based services (47.0%) compared with 33.7% of privately insured and 36.4% of children with combined insurance

### 3.3. Amount of types of current service use

Amount of types of service currently used in the public insurance alone group was 0.99 (standard deviation [SD]:1.1), 1.26 in the private insurance alone group (SD: 1.2), and 1.42 in the combined insurance group (SD: 1.4). In unadjusted log-Poisson models estimating prevalence ratios (PR), children with either private insurance alone or combined insurance used a greater amount of types of community-based services compared to children with public insurance alone (Table 3). After adjustment for confounding, children with private insurance alone had 0.83 times the categories of service use compared to children with public insurance alone, but this result was not statistically significant with the confidence interval including the null (95% CI 0.67, 1.03).

### 3.4. Odds ratios by insurance status

When we examined the use of specific services by insurance status (Table 3), we found increased unadjusted-odds of receiving community-based behavioral therapy in children on private insurance only or combined insurance compared to children on public insurance. After adjusting for confounders our results were attenuated when comparing children with private insurance only (adjusted Odds Ratio [aOR]: 1.81; 95% CI 0.85, 3.85) and combined insurance (aOR: 2.34; 95% CI: 1.02, 5.35) to public insurance alone. We found a negative association between being on private insurance and psychotropic medication prescription, with children on private insurance alone having 0.32 times the adjusted odds of having a prescription compared to children on public insurance alone (95% CI: 0.14,0.71). In our sensitivity analysis incorporating school-based services, our estimates did not meaningfully change (Supplement 2). We note that children received no in- or out- of school services (12.0%) and 212 (26.7%) received in-school service only.

**Table 1**

Demographic characteristics of children with previous diagnosis of autism spectrum disorder in the Study to Explore Early Development, by insurance status.

	All		Public insurance alone		Private insurance alone		Combined insurance	
	N = 792		N = 279		N = 406		N = 107	
	N	%	N	%	N	%	N	%
<b>Maternal race</b>								
White	465	58.8	115	41.2	270	66.5	80	74.8
Black	216	27.3	138	49.5	61	15.0	17	15.9
Asian	63	8.0	7	2.5	51	12.6	5	4.7
Other	47	5.9	18	6.5	24	5.9	5	4.7
Missing	1		1					
<b>Hispanic ethnicity</b>								
Hispanic	109	14.0	54	19.7	40	10.1	15	14.0
Non-Hispanic	669	86.0	220	80.3	357	89.9	92	86.0
Missing	14		5		9			
<b>Maternal education</b>								
< High school degree	31	3.9	25	9.0	4	1.0	2	1.9
High school degree	77	9.8	52	18.8	15	3.7	10	9.3
Some college	259	32.8	131	47.3	104	25.7	24	22.4
≥ Bachelor's degree	423	53.6	70	25.3	282	69.6	71	66.4
Missing	2		1		1			
<b>Child sex</b>								
Male	639	80.7	230	82.4	325	80.0	84	78.5
Female	153	19.3	49	17.6	81	20.0	23	21.5
<b>Child year of birth</b>								
2008	245	30.9	87	31.2	124	30.5	34	31.8
2009	216	27.3	75	26.9	115	28.3	26	24.3
2010	206	26.0	69	24.7	105	25.9	32	29.9
2011	125	15.8	48	17.2	62	15.3	15	14.0
<b>Year of study completion</b>								
2010	1	0.1	1	0.4	0	0.0	0	0.0
2012	110	13.9	32	11.5	63	15.5	15	14.0
2013	222	28.0	78	28.0	116	28.6	28	26.2
2014	181	22.9	61	21.9	102	25.1	18	16.8
2015	256	32.3	99	35.5	115	28.3	42	39.3
2016	22	2.8	8	2.9	10	2.5	4	3.7
<b>Final SEED Case Classification</b>								
ASD	666	84.1	227	81.4	345	85.0	94	87.9
DD	126	15.9	52	18.6	61	15.0	13	12.1
<b>ADOS Severity Score</b>								
< 7	332	42.0	126	45.2	157	38.9	49	45.8
> = 7	458	58.0	153	54.8	247	61.1	58	54.2
Missing	2				2			
<b>Child age at clinic visit (months)</b>								
Median, IQR	57.0	12.9	57.5	13.5	56.2	12.9	58.6	11.3
<b>Social Communication Questionnaire score</b>								
Median, IQR	17.0	9.5	18.0	8.0	15.0	9.0	18.0	10.0
<b>Site</b>								
California	134	16.9	24	8.6	99	24.4	11	10.3
Colorado	116	14.6	46	16.5	59	14.5	11	10.3
Georgia	174	22.0	84	30.1	69	17.0	21	19.6
Maryland	140	17.7	43	15.4	89	21.9	8	7.5
North Carolina	120	15.2	39	14.0	71	17.5	10	9.3
Pennsylvania	108	13.6	43	15.4	19	4.7	46	43.0
<b>Income in past 12 months</b>								
< \$30,000	197	24.9	167	61.4	16	4.0	14	13.5
\$30,000-\$90,000	325	41.0	103	37.9	175	44.2	47	45.2
> \$90,000	252	31.8	4	1.5	205	51.8	43	41.3
Missing	18	2.3	5		10		3	
<b>Children living in the household</b>								
1	212	26.8	80	28.7	106	26.2	26	24.3
2	374	47.3	96	34.4	225	55.7	53	49.5
3+	204	25.8	103	36.9	73	18.1	28	26.2
Missing	2				2			

ADOS: Autism Diagnostic Observation Schedule, higher score indicates more severe presentation.

IQR: Inter quartile range.

ASD: Autism spectrum disorder.

DD: Developmental disability.

N = 11 were uninsured at time of enrollment.

**Table 2**

Amount of community-based service types used and specific service types currently used by children with a previous diagnosis of ASD at enrollment into the Study to Explore Early Development, by insurance status.

	All		Public insurance alone		Private insurance alone		Combined insurance	
	N = 792		N = 279		N = 406		N = 107	
	N	%	N	%	N	%	N	%
<b>Amount of service types used</b>								
0	307	38.8	131	47.0	137	33.7	39	36.4
1	207	26.1	66	23.7	121	29.8	20	18.7
2	148	18.7	44	15.8	82	20.2	22	20.6
3	95	12.0	30	10.8	45	11.1	20	18.7
4	24	3.0	8	2.9	13	3.2	3	2.8
5	9	1.1	0	0.0	7	1.7	2	1.9
6	2	0.3	0	0.0	1	0.2	1	0.9
<b>Specific service</b>								
Speech therapy	289	36.5	94	33.7	155	38.2	40	37.4
Occupational therapy	230	29.0	76	27.2	117	28.8	37	34.6
Behavior therapy	161	20.3	24	8.6	112	27.6	25	23.4
Medication	82	10.4	33	11.8	39	9.6	10	9.3
Social Skills training	51	6.4	15	5.4	27	6.7	9	8.4
Respite care	48	6.1	11	3.9	29	7.1	8	7.5
Physical therapy	33	4.2	11	3.9	14	3.4	8	7.5
CHA	14	1.8	5	1.8	6	1.5	3	2.8
Other	31	3.9	6	2.2	13	3.2	12	11.2

CHA: Complementary health approaches.

CHA includes chelation, chiropractic, immune treatments, and hyperbaric oxygen therapies.

Medication includes: anti-depressants, atypical antipsychotics, seizures or mood stabilizers, non-stimulants for hyperactivity, stimulant medications for hyperactivity.

Children without insurance were not included due to small sample size.

Other services are listed in supplement 1b.

### 3.5. Impact of ASD severity

The cumulative amount of service types used was greater for those with higher ASD symptom severity (mean service types used: 1.36, SD: 1.3) compared to those with lower ASD symptom severity (mean: 0.94, SD 1.1). There was no association between amount of service types used and insurance status within strata of severity (Table 4). Among children with more severe ASD, the odds of community-based behavioral therapy were higher among those with private insurance alone compared to children with public insurance alone (aOR 3.06, 95% CI 1.23, 7.59). Among the lower severity group, children with combined insurance had higher odds of community-based behavioral therapy compared to children with public insurance alone (aOR 4.88, 95% CI 1.23, 19.33).

## 4. Discussion

Relatively little descriptive epidemiological work has assessed patterns in community-based service use for preschool age children with ASD. Understanding these patterns is important given that services received in the preschool years are associated with improved development outcomes later in life (Kogel et al., 2014; Landa & Kalb, 2012). In a sample of 3–5-year-old children between 2012 and 2016 with previously diagnosed ASD, 40% were not receiving community-based services and one-quarter received only one community-based service at time of study entry. We found distinct differences based on insurance status, which may illustrate a disparity in service access.

In terms of amount and categories of service use, our results were similar to findings reported for preschool children with ASD, with speech therapy and OT being most common services (Stahmer, Suhrheinrich, & Mandell, 2016). In data with similar methodology from California, Akins, Krakowiak, Angkustsiri, Hertz-Picciotto, and Hansen (2014) also found highest use of speech therapy (91.4%) and OT (71.6%) in a sample of preschool age children with ASD. Estimates were higher than we saw in our sample and differences may be because our study assessed a wide sample of children who ever had an ASD diagnosis, a target sample not limited to children with clinically confirmed ASD diagnosis. Alternatively, the California sample may have a different pattern of insurance enrollment compared to our sample. In other studies using different sampling methods, results were in line with our findings; Mire, Raff, Brewton, and Goin-Kochel (2015) assessed data from the Simons Simplex Collection and found approximately 30% of children 3–5 with ASD had private speech therapy and approximately 20% had private OT. Payakachat et al. (2018) looked at service use in preschoolers registered in the Autism Speaks Treatment Network and found speech therapy was most widely used followed by OT, and only 28% of children had behavioral therapy.

In assessing how service patterns differ by insurance status, we did not see statistically significant differences between amount of types of community-based service received between public and private insurance after adjustment for confounding. Although the adjusted result did not meet statistical significance, the negative association of the adjusted effect estimate is in line with previous studies (Wang et al., 2013; Zhang & Baranek, 2016). We may see less service use in children enrolled in private insurance alone

**Table 3**

Associations between current community-based service use and insurance status in children with previous diagnosis of autism spectrum disorder at time of enrollment in the Study to Explore Early Development.

	Unadjusted			Adjusted		
	OR	95% CI		OR	95% CI	
<b>Amount of service types used<sup>a</sup></b>						
Public	REF			REF		
Private	<b>1.18</b>	1.02	1.38	0.83	0.67	1.03
Both	<b>1.61</b>	1.32	1.98	1.17	0.92	1.49
<b>Speech therapy</b>						
Public	REF			REF		
Private	1.18	0.84	1.64	0.93	0.58	1.51
Both	1.45	0.89	2.36	1.19	0.67	2.12
<b>Occupational therapy</b>						
Public	REF			REF		
Private	1.10	0.63	1.29	0.66	0.39	1.13
Both	<b>1.85</b>	1.76	1.95	1.24	0.68	2.29
<b>Behavioral therapy</b>						
Public	REF			REF		
Private	<b>2.96</b>	1.80	4.87	1.81	0.85	3.85
Both	<b>4.23</b>	2.15	8.30	<b>2.34</b>	1.02	5.35
<b>Medication</b>						
Public	REF			REF		
Private	0.78	0.47	1.30	<b>0.32</b>	0.14	0.71
Both	0.84	0.39	1.83	0.49	0.19	1.27
<b>Social skills training</b>						
Public	REF			REF		
Private	1.25	0.65	2.40	0.70	0.28	1.71
Both	1.62	0.69	3.81	0.97	0.35	2.68
<b>Respite care</b>						
Public	REF			REF		
Private	0.90	1.94	0.42	0.90	0.30	2.71
Both	2.46	0.87	6.97	2.41	0.72	8.07
<b>Physical therapy</b>						
Public	REF			REF		
Private	0.94	0.42	2.13	0.49	0.16	1.54
Both	2.13	0.82	5.55	0.99	0.29	3.38

OR: odds ratio.

REF: reference group.

CI: confidence interval.

Adjusted models controlled for income, number of children in home, maternal education, race, and ethnicity, child year of birth and site as a random intercept.

Medication includes: anti-depressants, atypical antipsychotics, seizures or mood stabilizers, non-stimulants for hyperactivity, stimulant medications for hyperactivity.

Other and CHA did not have adequate sample size to assess.

Bold indicates statistical significance at an alpha = 0.05 level.

N = 32 (4%) observations dropped due to missing covariate data.

\* Amount of service types used log-Poisson regression to estimate prevalence ratios, all other estimates are odds ratios derived from logistic regression.

because the private insurers were more prohibitive in covering ASD services, meaning a family has to pay more out of pocket (Wang et al., 2013). While state level insurance mandates requiring private insurers to cover ASD-related services have been enacted, the resulting effects in service coverage has been gradual (Barry et al., 2017). Another hypothesis is that the children in most need of service with private insurance may be more likely to be dual enrolled in Medicaid through programs like Katie Beckett waivers (state waivers that cover children who need an institutional level of care without the income requirements of Medicaid) or HCBS waivers (Miller et al., 2016).

The movement of our estimates towards or beyond null after adjustment for variables like maternal education, race, and income is consistent with the disparity due to race and other socioeconomic characteristics seen when assessing any service use for children with ASD (Broder-Fingert, Shui, Pulcini, Kurowski, & Perrin, 2013; Locke et al., 2017; Payakachat et al., 2018). The effect of socioeconomic status and demographic characteristics on the association between insurance status and service use may indicate that insurance status (among those insured) is not the primary driver of differences in service use (Chou, Tulolo, Raver, Hsu, & Young, 2013). The impact of other non-insurance sociodemographic characteristics may be especially important since we could not

**Table 4**

Prevalence and odds ratios for amount of current community-based service types used comparing insurance status in children with a previous diagnosis of autism spectrum disorder in the Study to Explore Early Development, stratified by Autism Diagnostic Observation Schedule Severity score.

	ADOS severity > = 7				ADOS severity < 7			
	%	OR <sup>A</sup>	95% CI		%	OR <sup>A</sup>	95% CI	
<b>Amount of service types used<sup>†</sup> (PR)</b>								
Public	1.73	REF			1.13	REF		
Private	1.58	0.92	0.70	1.21	0.88	0.77	0.54	1.11
Both	2.14	1.24	0.92	1.68	0.99	0.88	0.57	1.35
<b>Behavioral therapy</b>								
Public	12.1	REF			5.0	REF		
Private	34.0	<b>3.06</b>	1.23	7.59	19.6	1.18	0.35	3.95
Both	21.1	1.97	0.69	5.61	25.5	<b>4.88</b>	1.23	19.33
<b>Medication</b>								
Public	13.4	REF			10.9	REF		
Private	9.7	0.40	0.16	1.02	7.4	0.46	0.12	1.71
Both	14.0	0.67	0.23	1.94	2.1	0.21	0.02	2.09

PR prevalence ratio.

OR odds ratio.

CI confidence interval.

Specific therapies chosen based on adequate sample size and significant findings in non-stratified sample.

Adjusted for income, number of children in home, maternal education (no college or college or greater), race (white or non-white), and ethnicity, child year of birth and site as a random intercept.

Medication includes: anti-depressants, atypical antipsychotics, seizures or mood stabilizers, non-stimulants for hyperactivity, stimulant medications for hyperactivity.

N = 32 missing covariate data and dropped from model (5.4% of ADOS score < 7, 3.1% of ADOS score > = 7).

Bold indicates statistical significance at an alpha = 0.05 level.

\* Amount of service types used log-Poisson regression to estimate prevalence ratios, all other estimates are odds ratios derived from logistic regression.

determine which therapies or services were covered by insurance providers and which were paid for out-of-pocket. Such unmeasured variables could include knowledge of the health care system and distance to service providers. Out-of-pocket expenses are more likely among families of children with private insurance alone, likely due to the increased income that may allow a family to pay additional service-expenses (Zhang & Baranek, 2016). More work is needed to assess whether there are multiplicative effects between insurance status and disparity of service use (i.e. children in a racial minority group and on Medicaid receive fewer services than white children on Medicaid), which might clarify what populations to target to irradicate this service gap. To build on this work, we aim to further explore the impact of the medical home, or a team health care delivery model, on how these children receive services.

There were stark differences in receipt of behavioral therapy by insurance status; children with public insurance alone were least likely to receive community-based behavioral therapy. Our finding is in contrast to Wang et al. (2013), who found more behavioral therapy visits among children enrolled in Medicaid, although they assessed 2003 Medicaid claims of children ≤17 years old. It is important that all young children with ASD have access, both in availability and affordability, to appropriate behavioral therapies so they have opportunities to advance skill development and maximize future potential. While our study did not assess the individual family's reason for not using behavioral therapy or the quality of therapy received, a potential explanation for the gap we saw is a lack of access for children of low socioeconomic status, as indicated by public insurance status. In our sample, children on public insurance alone were less likely to receive behavioral therapy and these children were more likely to be prescribed medications. Similar to our findings on behavioral therapy, we cannot be certain whether the medication allocated was appropriate or whether it was fully driven by socioeconomic differences. Our finding was consistent with past literature (Houghton, Ong, & Bolognani, 2017; Jackel et al., 2017). A hypothesis for the difference in prescribing practice we see in our study and in the literature is that differences may be a result of suboptimal prescribing practice; or, the lack of access to and knowledge about behavioral therapies for a child of lower socioeconomic status leads to greater reliance on psychotropic medication (Houghton et al., 2017; Jackel et al., 2017). Improving availability and insurance coverage for other services, like behavioral therapy, may be one way to reduce the reliance on potentially unnecessary medication. Further approaches may also alter prescribing practice, including continued work in creating and adapting implementable community-based behaviorally based ASD interventions (Vivanti et al., 2018), and promoting provider education about ASD, appropriate services and prescribing, and medical homes (Nolan, Walker, Hanson, & Friedman, 2016). Across service types, innovative delivery models, such as family navigation, can empower families in lower-income settings advocate and receive for optimal care (Broder-Fingert et al., 2018; Parellada et al., 2013).

Our data indicate that ASD severity was associated with the amount of service types used, as children in the higher ASD-severity group received more types of services. This aligns with the hypothesis that children with more severe presentations may be tried on more services as a way to broaden the chance of finding a successful intervention (Akins et al., 2014; Rubenstein et al., 2018). In each strata of severity, insurance status was only associated with receipt of community-based behavioral therapy. These results are difficult

to interpret due to our cross-sectional design, since we cannot determine whether current or past service use has altered severity, nor do we know the insurance status the child had in the past. Children with more severe presentation may have greater medical necessity which increases ability to get behavioral therapy under private insurance systems (Douglas et al., 2017). More research is needed into the effect of state insurance mandates on service use at the individual level, aiming to see if these laws specifically helped children with a more severe presentation.

Our study was limited by the single time point of data collection, preventing examination of the association between insurance status and service use prior to the time of study enrollment. Also, minimal details about services were available, including the number of hours, mode of delivery, and whether the insurer covered the service. We hope to assess these questions in the future using administrative data. Reporting on service use could have been impacted by recall bias due to varying amount of time since a service was used and the respondents understanding of the questions. Both insurance status and service use were reported by the mother and were not validated with medical records. It is additionally possible that the child received all needed service in the school setting and community-based service was not necessary. Although our sample was community-based and multi-site, the SEED sample is of a higher socioeconomic status than the underlying population and is only a sample from six states-results may not be generalizable to other samples or other states. Sample size was not large enough sample to examine the impacts of changes in state insurance laws, mandates, and waivers. State level differences were adjusted for by using study site as a random intercept, but with a larger sample, site level effects could be assessed. Finally, these data were collected between 2012 and 2016, so service use may have been impacted by policy changes (i.e. implementation of the Affordable Care Act) and preferences and trends which we were unable to quantify.

## 5. Implications

This study found that many preschool age children with a past ASD diagnosis did not receive community-based services, especially behavioral therapy. Children on public insurance only were more likely to receive medication and less likely to receive behavioral therapy compared to children with any private insurance. Because receiving adequate service is important in order for young children with ASD to receive optimal outcomes, enacting policies like Medicaid HCBS waivers and increased funding to reduce waitlists may increase availability for these much desired services. Promoting practices like medical homes and pediatrician education may improve care and care coordination once a child is in the health care system. Implementing community- and evidence-based intervention outside of clinic setting can also close disparity related gaps. Ultimately, improving the availability of evidence-based services to children in all types of insurance programs will increase service use and lead to improved outcomes.

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## Appendix A. Supplementary data

Supplementary material related to this article can be found, in the online version, at doi:<https://doi.org/10.1016/j.rasd.2019.101410>.

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