Administration and Policy in Mental Health and Mental Health Services Research (2022) 49:694–705
https://doi.org/10.1007/s10488-022-01192-4

ORIGINAL ARTICLE

Lifespan service receipt and unmet needs among individuals on the autism spectrum

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Accepted: 15 February 2022 / Published online: 23 March 2022

Abstract

Timely data on service use and needs across the lifespan are essential to developing an effective and efficient service delivery system that is responsive to developmental issues. This study uses data from one of the largest statewide surveys conducted between 2017 and 2018 to compare service use and unmet needs among individuals on the autism spectrum across the lifespan. A statewide sample of 5792 caregivers of autistic children and adults were included in the study. Logistic regressions were conducted to compare service use and need among six age groups ranging from early childhood (0–5 years) to later adulthood (31+) while adjusting for sociodemographic characteristics. We found that the transition-age adult group (18–21 years) was less likely to receive services, including speech/language therapy, occupational therapy, one-on-one support, and social skill training, than adolescents. However, case management and mental health services increased with age. Young adults (22–30 years) were more likely to report unmet needs than both adolescents and transition-age adult groups. The use of services overall decrease and service needs increased compared to results from an earlier statewide survey that was conducting in 2009–2010. These results can be used to inform developmentally appropriate autism-related healthcare policies and service development and delivery. This study offers a more detailed look at differences between adult age subgroups that are novel. Further research is needed about the prevalence of ASD in adulthood, clinical trajectories, and outcomes in order to support autistic adults in getting the appropriate services and supports.

Keywords Autism spectrum disorder · Service use · Service needs · Lifespan · Adults

A significant amount of attention has been paid to children and adolescents on the autism spectrum, but autism spectrum disorder (ASD) is a life-long developmental disability. Although some symptoms may diminish, stay the same, or emerge over time, most aspects of the diagnosis, such as social communication and adaptive behaviors, typically endure (Meyer et al., 2018). As individuals on the autism spectrum age, services and supports are often needed to adapt to various developmental stages and circumstances (Cidav et al., 2013; Turcotte et al., 2016). Moreover, the presence of complex, co-occurring medical and mental health conditions that may occur over time (Cassidy et al., 2014; Croen et al., 2015; Gotham et al., 2015) also requires a different mix of services to address individual needs. Timely data on service use and needs across the lifespan are essential to developing an effective and efficient service delivery system responsive to developmental issues.

Service utilization seems to reflect an age-specific pattern given that the health and service needs change across the life course. For example, early assessment and intervention (Howlin et al., 2009), therapy services (Hyman et al., 2020; Yingling & Bell, 2020), and behavioral support (Lai & Weiss, 2017; Siegel & King, 2014) are most often used by children. A recent National Autism Indicators Report analyzing the National Survey of Children's Health and Medical Expenditure Panel Survey data found that younger children

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(ages 3–11) were more likely to receive ASD-related behavioral interventions than older children (ages 12–17) (Rast et al., 2020). In comparison, older children were more likely to report the receipt of mental health services and medication use than younger children (Rast et al., 2020). Services focused on life skills, community programs, and employment are typically needed in adolescence and as individuals age into adulthood (Lai & Weiss, 2017; Shattuck et al., 2011). Postsecondary education supports and vocational services are also crucial to success in the transition to adulthood (Roux et al., 2016; Shattuck et al., 2012). A subset of services, like social skills, are needed across the lifespan to address social and communication needs that are present throughout all developmental stages (Lai & Weiss, 2017).

Not all autistic individuals can access the services that they need. The complex health needs of individuals on the autism spectrum may be driven by clinical factors, including ASD symptom severity, co-occurring intellectual disability (ID), medical conditions, and psychiatric disorders (Lindly et al., 2020; Vohra et al., 2017; Zablotsky et al., 2015). These clinical presentations may demand additional services and support for behavioral problems, social skills, and mental health. At the same time, service access is impacted by parental knowledge of the service system and socioeconomic status (Pickard & Ingersoll, 2016; Lindly et al., 2019). For instance, compared with parents with a 4-year college or higher education, parents without a 4-year college education had less knowledge of autism services, which was associated with lower service use of their autistic child (Pickard & Ingersoll, 2016). They also reported more structural barriers, such as work schedule and transportation, to access services for their autistic child (Pickard & Ingersoll, 2016).

Systematic factors, such as aging out school supports (e.g., Individualized Education Program) under Individuals with Disabilities Education Act (IDEA), have been predictive of reduced receipt of outpatient services among young autistic adults, including speech therapy, occupational therapy, and respite services (Nathenson & Zablotsky, 2017; Laxman et al., 2019), though service needs remain for this group (Taylor & Henninger, 2015). State Medicaid Home and Community-based Services programs (HCBS) offer services to help people with special needs continue to live in their homes and communities (Velott et al., 2016). However, these Medicaid waiver programs disproportionately benefited children from high-income households and did not ameliorate unmet needs for ASD-specific services (Leslie et al., 2017). In response to the continued gaps in ASD services and high public-sector burden, all 50 U.S. states and the District of Columbia have passed laws requiring private insurance plans to cover ASD treatment and services (e.g., Applied Behavior Analysis, therapy services), as of 2019 (known as autism mandates; Autism Speaks, n.d.). However, these mandates have age caps that often end during adolescence or up to 21 years of age, which exclude autistic adults from benefits altogether. Evidence has shown that age caps are associated with a lower probability of using autism services and lower spending on ASD-related outpatient services among those who have exceeded mandated age caps (Kennedy-Hendricks et al., 2018).

The myriad of perceived service needs present during each stage of development and the awareness of limited service access require studying long-term service needs and prioritizing service provision. At the same time, there is an increasing need to understand the needs of individuals in the transition to adulthood and beyond because benefits rarely extend past young adulthood after the end of the entitlement to services through the education system or linkages to parent-based private insurance (Patient Protection and Affordable Care Act, 2010). In the case of this study, it is essential to know whether service use patterns and needs are changing in response to the increased interest for autistic adults. Previous studies that have explored the variation in service use and need in different developmental stages (e.g., Lai & Weiss, 2017; Rast et al., 2020; Turcotte et al., 2016) have insufficient reporting on the service needs of autistic adults. Turcotte and colleagues (2016) used statewide data collected in 2009–2010 and found that caregivers of autistic adults reported higher unmet needs for speech and language therapy, occupational therapy, social skill training, and one-to-one support than caregivers of children and adolescents on the autism spectrum. However, the research base focused on ASD has changed. We do not know whether these rates have remained for autistic adults in more recent data. The rising prevalence of ASD (i.e., from 1:68 in 2010 to 1:54 children in 2016) (Maenner et al., 2020) and an increasing number of autistic adults (Dietz et al., 2020) result in higher demand for autism-specific support. This heightens the importance of examining changes in service use and the extent to which needs are being addressed over time.

The present study offers an update to understanding service use and unmet needs across age groups by using autism-specific statewide data gathered in a large Northeastern state in 2017–2018 and using nearly the same methods as Turcotte et al.'s (2016) study. Our study adds to prior work documenting lifespan service use and needs for individuals on the autism spectrum in the 2009–2010 dataset used in Turcotte et al.'s (2016) study. The two surveys were conducted eight years apart. One research question of this study was whether service use disparities observed previously remained, such as autistic adults receiving fewer services than their younger peers and autistic adults being more likely to have unmet needs in multiple service areas, especially psychosocial training and therapy services.

Another research question addressed the gaps in the existing research by reporting service use and needs of adults compared to younger age groups. Specifically, this study further broke down the adult sample (18+) into specific, meaningful cohorts - transition-age adults, young adults, and later adulthood to gain a more fine-tuned understanding of how service use and needs may change in adulthood.

Method

Data and Sample

Data for this study were generated from the Pennsylvania Autism Needs Assessment survey, conducted between May 2017 and June 2018. The survey was the second iteration of a statewide survey of individuals on the autism spectrum and their caregivers. It assessed an array of demographic characteristics, diagnosis, health insurance coverage, service use, service needs, and satisfaction with health services. Survey modules and summary reports are publicly accessible at https://needs.paautism.org/. The study's inclusion criteria were to be an individual on the autism spectrum or a caregiver of an individual on the autism spectrum. There was no age limit for individuals on the autism spectrum.

The study used two methods to recruit participants. First, survey invitation letters were mailed to all Pennsylvania residents of all ages enrolled in Medicaid and had a claim or encounter with an ASD diagnosis (International Classification of Disease-9 299.XX or International Classification of Disease-10 F84.X) at any point between 2005 and 2017. One ASD-related claim has shown a positive predictive value of up to 75%, and administrative claims sampling has been tested in a variety of algorithms to most accurately predict an ASD diagnosis (Bickford et al. 2020; Burke et al. 2014). Previous studies have used it to identify ASD samples (e.g., Mandell et al. 2016; Stein et al. 2012). The letter mailing was in collaboration with the Pennsylvania Department of Human Services, Bureau of Supports for Autism and Special Populations, which commissioned the Pennsylvania Autism Needs Assessment. The collaboration allowed the letters to be sent to all potential participants in Pennsylvania. The letter invitation to complete the survey was in English and Spanish. It explained the purpose of the study and provided a website link where participants could go to complete the survey online. A contact phone number and email were also provided so that individuals could request a paper copy of the survey. Participants could also call a phone line to request assistance in completing the survey.

Second, the survey was also distributed through ASD-specific advocacy and policy organizations to encourage broad participation. Similarly, numerous options were offered to prospective participants, including web-based, paper, and phone-based completion of the survey (with a research team member). The survey was translated into 14 languages by a certified translation company. If a non-English survey was completed, answers were recorded into an English Version by individuals fluent in both languages. Study procedures were approved by the Drexel University Institutional Review Board.

Caregivers of individuals on the autism spectrum of all ages completed the survey, and autistic adults (aged 18 years or older) completed the survey for themselves. No functional restrictions were imposed on completing the survey. This study used responses from caregivers of autistic individuals of all ages. A total of 6,713 caregivers responded to the survey, which was almost double the sample size from the first administration in 2009–2010 (i.e., 3,440). Most of the respondents were mothers (81%), also small percentages of fathers (12%), and other caregivers (7%). Only a small number of respondents responded to a non-English survey (i.e., 23 Spanish, four Russian, and five others). Given the focus of this study on age-related differences, the final sample included respondents who provided a valid age or birthday of the individual they were responding about, which decreased the sample by 921 responses (14%), leaving a final sample of 5,792 responses.

Measures

Service measures. As part of the data collection, participants provided information on their ASD-related service use and unmet service needs. Twenty-four widely used services by autistic individuals of all ages were probed in the survey, including mental and behavioral health services (e.g., mental health counseling, behavioral support), functional skill services (e.g., physical therapy, occupational therapy, mobile therapy, and social skills training), employment and educational services (e.g., employment support services, vocational support services), physical health services (e.g., medication management, neurological services), and case management. Caregivers were presented with the following question "Please tell us about your child's health and education service needs. My child is receiving this service" and chose from the options, "Yes" or "No." Then caregivers responded to a follow-up question, "Does your child need more of this service?" and chose from the options, "Yes" or "No." Respondents were considered to report unmet service needs when they responded "no" to receiving the services but "yes" to needing more of this service. This ensured that outcomes were consistent with Turcotte et al.'s (2016) study. As the Turcotte et al.'s (20,116) study, the examined services included speech/language therapy, occupational therapy, physical therapy, social skills training, one-to-one support/behavioral support, case management/support coordination, neurology services, and medication management.

Age groups. One difference between this study and Turcotte et al. (2016) is that age groupings were used rather than school placement (i.e., elementary school, middle/high school). The age groups included early childhood (aged 0–5), middle childhood (aged 6–11), adolescence (aged 12–17), transition-age adults (aged 18–21), young adults (aged 22–30), older adults (aged 31 and above).

Covariates. Sociodemographic variables included gender (male vs. female), race and ethnicity (i.e., non-Hispanic White, non-Hispanic Black, and other), and location of residence (urban, suburban, and rural). The rural-urban designation to individuals was based on zip-code derived Rural-Urban Commuting Area (RUCA) category. Coexisting mental health diagnoses were identified if participants noted the presence of one or more psychiatric diagnoses, such as anxiety, depression, attention-deficit/hyperactivity disorder (ADHD), and bipolar disorder. A dichotomous variable indicated whether the participant had an ID diagnosis or not. Regarding insurance status, participants answered the question, “Are you covered by any of the following kinds of health insurance: (1) Private health insurance that you or a family member receive through employment; (2) Private health insurance that you or a family member purchases; (3) Medicaid, CHIP, or Medicare;“ and other types of insurance (including veteran’s benefits or TRICARE, dental insurance, vision insurance, insurance that covers prescription medications, and others). Participants could indicate more than one type of insurance coverage. The first two options were combined to represent private insurance. We coded insurance status into four categories: (1) private insurance alone, (2) public insurance alone, (3) combined insurance (both private and public insurance), and (4) other insurance or no insurance.

Table 1 Sociodemographic and Clinical Factors for Study Sample Based on Caregiver Reports of Individuals with ASD by Age Group

	Early childhood (n = 489)	Middle childhood (n = 1538)	Adolescence (n = 1903)	Transition-age adults (n = 727)	Young adults (n = 685)	Older adults (n = 212)	Total (N = 5792)	χ^2(df)
	n, %	n, %	n, %	n, %	n, %	n, %	n, %	
Gender								12.5 (5)*
Male	376, 78	1243, 82	1509, 78	613, 79	612, 79	164, 73	4517, 79	
Female	104, 22	281, 18	431, 22	165, 21.2	160, 21	60, 27	1201, 21	
Race/Ethnicity								92.7 (10)***
Non-Hispanic White	320, 69	1069, 712	1507, 80	595, 78	608, 82	173, 79	4272, 77	
Non-Hispanic Black	40, 9	109, 7	102, 5	52, 6.8	66, 9	27, 12	396, 7	
Other	104, 22	312, 21	287, 15	121, 16	72, 10	20, 9	916, 16	
Location of residence								16.5 (10)
Urban	106, 23	270, 18	321, 17	144, 19	152, 20	33, 15	1026, 19	
Suburban	258, 55	825, 56	1073, 57	409, 54	418, 56	117, 55	3100, 56	
Rural	103, 22	381, 26	493, 26	208, 27	176, 24	64, 30	1425, 26	
Annual household income								92.5 (20)***
Under $10,000	55, 12	154, 11	104, 6	37, 5	27, 4	15, 7	392, 7	
$10,000-$19,000	49, 11	163, 11	162, 9	60, 8	59, 8	22, 11	515, 10	
$20,000-$29,999	65, 14	157, 11	184, 10	67, 9	66, 9	19, 9	558, 11	
$30,000–$49,999	38, 8	137, 10	181, 10	58, 8	67, 10	26, 13	507, 10	
$50,000 or above	255, 55	830, 58	1172, 65	500, 69	480, 69	121, 60	3358, 63	
Insurance status								237.5 (15)***
Private only	18, 4	96, 6	161, 8	102, 13	122, 16	9, 4	508, 9	
Public (Medicaid) only	207, 42	676, 44	771, 39	264, 33	348, 45	148, 65	2414, 42	
Private and public	191, 39	639, 42	890, 45	360, 45	237, 30	40, 18	2357, 41	
Other or no insurance	73, 15	127, 8	140, 7	68, 9	75, 10	30, 13	513, 9	
Mental health diagnoses	123, 25	826, 53	1309, 67	483, 61	472, 60	129, 57	3342, 58	293.2 (5)***
Intellectual disability diagnosis	14, 3	120, 8	284, 15	210, 26	239, 31	86, 38	953, 17	401.8 (5)***
	Mean, SD	Mean, SD	Mean, SD	Mean, SD	Mean, SD	Mean, SD	Mean, SD	F test (df)
Age at the time of survey	4.05, 1.1	8.7, 1.7	14.4, 1.7	19.3, 1.1	25.07, 2.439	40.1, 11.7	15.1, 8.4	8729.2 (5)***
Age at diagnosis	2.6, 1.2	3.9, 2.0	6.8, 48.9	6.0, 4.1	6.7, 5.0	12.3, 12.0	5.7, 28.8	4.3 (5) ***

Note. ***$p < 0.001$, **$p < 0.01$, * $p < 0.05$

Analysis Plan

Logistic regression was used to calculate the odds ratio (OR) of whether receiving services and unmet needs of autistic individuals differ across age categories. Post-hoc comparisons examined the rates of service use and unmet service between age-related transitions. Specifically, early childhood was compared to children in middle childhood, adolescence to middle childhood and transition-age adults, and young adults to transition-age adults and older adults. The ORs and 95% confidence intervals (CIs) were adjusted for individual gender, race and ethnicity, residence location, presence of ID, mental health diagnoses, and insurance status. IBM SPSS 26.0 software was used for the analysis.

Results

Sample Characteristics

Demographic information of the sample is provided in Table 1. The sample of 5,792 autistic individuals for whom caregivers responded was primarily male (79%, $n=4{,}517$) and non-Hispanic White (77%, n = 4,272). The Chi-square test (χ^2=92.7, $p<0.001$) showed that the early childhood (69%) and middle childhood groups (71%) had relatively lower percentages of non-Hispanic White compared to the older groups. More than half of the respondents lived in suburban areas (56%, $n=3{,}100$); 26% of the sample lived in rural areas ($n=1{,}425$), and the remaining 19% lived in urban areas ($n=1{,}026$). Caregivers also reported the annual household income, with 63% ($n=3{,}358$) reporting an income of above $50,000. The Chi-square test (χ^2=92.5, $p<0.001$) showed that there is a lower percentage of caregivers in the early childhood (55%) and middle childhood groups (58%) having an annual household income of greater than $50,000 than the percentages of caregivers in the older groups. Most autistic individuals were covered either under public insurance alone (42%, $n=2{,}414$) or public and private insurance combined (41%, $n=2{,}357$). The older adults were more likely to be covered by public insurance only (65%) than their younger counterparts. More than half of the sample had mental health diagnoses (58%, $n=3{,}342$), with the early children being less likely to have mental health diagnoses (25%) than the older groups (χ^2=293.2, $p<0.001$). About 17% ($n=953$) had an ID diagnosis. The Chi-square test (χ^2 =401.8, p < 0.001) showed that the adult groups were more likely to have a co-occurring ID (ranging from 26% to 38%) than children and adolescent groups (ranging from 3% to 15%).

Service Use and Unmet Service Needs

Table 2 presents the percentages of individuals who received services or indicated an unmet need for services by age group. Table 3 present the ORs of the received services and unmet needs for services. Among the nine lifetime services, behavioral/one-on-one support was the most

Table 2 Service use and unmet needs among autistic individuals by age group, n, %

	Early childhood	Middle childhood	Adolescence	Transition-age adults	Young adults	Older adults	Total
Service received	n, %	n, %	n, %	n, %	n, %	n, %	n, %
Mental Health Counseling	48, 14	382, 31	652, 40	244, 39	241, 38	71, 42	1638, 35
Speech / Language Therapy	281, 78	773, 62	646, 40	179, 28	66, 10	26, 16	1971, 42
Occupational Therapy	236, 66	698, 56	495, 31	158, 25	79, 12	31, 18	1697, 36
Physical Therapy	111, 31	295, 24	267, 17	93, 15	63, 10	24, 14	853, 18
Social Skills Training	163, 47	569, 46	735, 45	211, 34	182, 29	56, 34	1916, 42
Behavioral/One-on-one support	215, 61	751, 61	740, 46	239, 38	262, 42	78, 47	2285, 49
Support coordination/case management	120, 34	409, 33	618, 38	261, 42	303, 48	111, 67	1822, 40
Neurology Services	61, 18	201, 17	309, 20	110, 18	121, 20	44, 28	846, 19
Medication Management	40, 12	313, 27	509, 34	170, 29	159, 27	58, 39	1249, 29
Unmet services (not receiving)							
Mental Health Counseling	73, 22	256, 22	299, 19	123, 21	113, 19	25, 16	889, 20
Speech / Language Therapy	31, 9	98, 8	117, 7	77, 13	128, 21	24, 15	475, 11
Occupational Therapy	35, 10	155, 13	248, 16	86, 14	135, 22	33, 21	692, 16
Physical Therapy	38, 12	131, 11	153, 10	76, 13	95, 16	28, 18	521, 12
Social Skills Training	106, 32	376, 32	524, 33	232, 39	281, 46	48, 31	1567, 35
Behavioral/One-on-one support	51, 15	194, 16	292, 19	132, 22	143, 24	33, 21	845, 19
Support coordination/case management	65, 20	212, 18	268, 17	127, 21	131, 22	16, 10	819, 19
Neurology Services	34, 11	141, 13	166, 12	67, 12	76, 14	25, 18	509, 12
Medication Management	14, 5	60, 6	118, 8	53, 10	56, 10	9, 7	310, 8

Table 3 Adjusted ORs (and 95% CIs) for service use and unmet needs

	Compare to early childhood	Compare to Adolescence		Compare to young adults	
	Middle childhood	Middle childhood	Transition-age adults	Transition-age adults	Older adults
Receiving services					
Mental Health Counseling	**2.49 (1.74, 3.59)**	**0.75 (0.63, 0.89)**	1.10 (0.88, 1.35)	0.92 (0.72, 1.19)	1.07 (0.72, 1.58)
Speech / Language Therapy	**0.51 (0.38, 0.68)**	**2.66 (2.25, 3.15)**	**0.46 (0.36, 0.58)**	**3.59 (2.56, 5.02)**	1.48 (0.88, 2.49)
Occupational Therapy	**0.66 (0.50, 0.86)**	**3.21 (2.71, 3.80)**	**0.61 (0.48, 0.77)**	**2.42 (1.75, 3.33)**	1.44 (0.88, 2.35)
Physical Therapy	**0.72 (0.54, 0.96)**	**1.64 (1.34, 2.00)**	0.85 (0.65, 1.12)	**1.81 (1.26, 2.61)**	1.25 (0.72, 2.16)
Social Skills Training	0.99 (0.77, 1.29)	1.09 (0.93, 1.28)	**0.57 (0.47, 0.71)**	1.28 (0.99, 1.66)	1.10 (0.74, 1.63)
Behavioral/One-on-one support	0.92 (0.70, 1.19)	**1.99 (1.69, 2.34)**	**0.67 (0.55, 0.83)**	0.82 (0.64, 1.05)	1.03 (0.71, 1.50)
Support coordination/case management	0.84 (0.64, 1.11)	0.86 (0.72, 1.01)	1.11 (0.91, 1.37)	0.81 (0.63, 1.05)	**1.75 (1.17, 2.62)**
Neurology Services	0.85 (0.60, 1.20)	0.94 (0.77, 1.16)	0.86 (0.66, 1.11)	0.90 (0.66, 1.22)	1.49 (0.97, 2.30)
Medication Management	**2.20 (1.47, 3.28)**	0.91 (0.76, 1.09)	0.87 (0.70, 0.10)	1.05 (0.79 1.38)	**1.65 (1.09, 2.50)**
Unmet needs (not receiving)					
Mental Health Counseling	0.90 (0.65, 1.23)	1.12 (0.92, 1.37)	1.08 (0.84, 1.38)	1.26 (0.92, 1.71)	0.90 (0.55, 1.48)
Speech / Language Therapy	0.78 (0.49, 1.22)	1.21 (0.90, 1.63)	**1.67 (1.21, 2.31)**	**0.62 (0.44, 0.86)**	0.62 (0.37, 1.03)
Occupational Therapy	1.264 (0.83, 1.93)	**0.78 (0.62, 0.99)**	0.86 (0.65, 1.14)	**0.57 (0.42, 0.79)**	0.95 (0.61, 1.49)
Physical Therapy	0.89 (0.59, 1.34)	1.16 (0.90, 1.51)	1.18 (0.87, 1.62)	0.79 (0.55, 1.13)	1.13 (0.69, 1.88)
Social Skills Training	0.98 (0.74, 1.30)	0.90 (0.76, 1.06)	**1.25 (1.01, 1.53)**	**0.71 (0.55, 0.91)**	**0.52 (0.35, 0.77)**
Behavioral/One-on-one support	1.08 (0.75, 1.55)	0.85 (0.69, 1.05)	1.22 (0.96, 1.57)	0.93 (0.69, 1.24)	1.02 (0.65, 1.59)
Support coordination/case management	0.90 (0.64, 1.26)	1.00 (0.81, 1.24)	**1.30 (1.01, 1.67)**	0.92 (0.68, 1.25)	**0.51 (0.29, 0.89)**
Neurology Services	1.20 (0.77, 1.87)	1.14 (0.88, 1.48)	1.01 (0.73, 1.40)	0.80 (0.55, 1.18)	1.56 (0.92, 2.63)
Medication Management	1.04 (0.54, 2.00)	**0.61 (0.43, 0.85)**	1.18 (0.82, 1.69)	0.93 (0.60, 1.44)	0.71 (0.33, 1.51)

Note. Bolded indicates statistical significance.

frequently used service (49%), followed by social skills training (42%), speech/language therapy (42%), and case management/ support coordination (40%). Other services, including occupational therapy (36%), mental health counseling (35%), and medication management (29%), were less commonly used. Neurology services (19%) and physical therapy (18%) were the least used among all services of interest. Regarding the unmet needs, social skills training was the most needed service (35%), followed by mental health counseling (20%), behavioral/one-on-one support (19%), and case management/ support coordination (19%). Parents least often indicated that medication management was needed. The results of age group differences below are presented for each service type. We organized the results based on the prevalence of service use.

Behavioral/one-to-one support. This service was most commonly received by young children and children (61% and 61% respectively). The likelihood of receiving the service in middle childhood was higher than in adolescence ($OR = 1.99, p < 0001$). Compared with adolescents, the likelihood of receiving the service was smaller for transition-age adults ($OR = 0.67, p < 0.001$). The percentages of using this service in young adult and older adult groups (42% and 47%) were similar to the transition-age adults (38%). No significant differences in rates of unmet needs were found across the planned comparisons (see Table 3).

Social skills training. The proportion receiving this service was very similar across the younger groups – early childhood (47%), middle childhood (46%), and adolescence (45%). However, the transition-age adult group was significantly less likely to receive social skills training than the adolescent group (33% vs. 45%; $OR = 0.57$, $p < 0.001$). There were no differences in the use of this service when comparing young adults to transition-age adults ($OR = 1.28$, $p = 0.065$) or older adults ($OR = 1.10$, $p = 0.652$). The transition-age adult group had a higher risk of unmet needs for social skills training than the adolescent group (39% vs. 33%; $OR = 1.25$, $p = 0.037$), while it had a lower risk of unmet needs than the young adult group (39% vs. 46%; $OR = 0.71$, $p = 0.006$). The older adult group had a significantly lower likelihood of having an unmet need for social skills training than the young adult group (31% vs. 46%; $OR = 0.52, p = 0.001$).

Speech/language therapy. This service was most commonly received by the early childhood group (78%), and then the proportion of receiving the service decreased as individuals aged (see Table 2). The likelihood of receiving this service was smaller when comparing the older group to the younger group except for comparing young adults and older adults (see Table 3). The rate of the use of this service was similar between young adult and older adult groups (10% vs. 16%; $OR = 1.48, p = 0.141$). Results of unmet needs showed that the transition-age group was more likely to report an unmet need for speech/language therapy than the adolescence group (13% vs. 7%; $OR = 1.67$, $p < 0.001$) yet less likely than the young adults (13% vs. 21%; $OR = 0.62$, $p < 0.001$).

Case management/support coordination. Percentages of receiving case management/support coordination were similar when comparing the younger group to the older group except for comparing young adults and older adults (see Table 3). Logistic regression detected a significant difference between young adults and older adults, where the older adults had a higher likelihood of receiving case management/support coordination than the young adults (67% vs. 48%; $OR = 1.75$, $p = 0.007$). There were significant differences in the likelihood of reporting unmet needs for case management/support coordination services between the adolescence and transition-age adult groups (17% vs. 21%; $OR = 1.30$, $p = 0.042$) and between young adult and older adult groups (21% vs. 10%; $OR = 0.51$, $p = 0.019$).

Occupational therapy. This service was most commonly used in early childhood (66%). The percentages of using this service gradually decreased in older groups and became stable in adulthood (see Table 2). The middle childhood group was slightly less likely to have unmet needs for occupational therapy than the adolescence group (13% vs. 16%, $OR = 0.78$, $p = 0.038$). There were no differences in unmet needs between adolescents and transition-age adults. The transition-age group had a lower likelihood of having unmet needs than the young adult group (14% vs. 22%; $OR = 0.57$, $p = 0.001$).

Mental health counseling. The proportion of children in middle childhood receiving mental health counseling services was significantly higher than the children in early childhood (31% vs. 13%; $OR = 2.53, p < 0.001$). The adolescent group also had a higher likelihood of receiving mental health counseling than the middle childhood group (40% vs. 31%; $OR = 2.49, p < 0.001$). The use of mental health counseling was not different between the adolescents and the transition-age adults or among adult groups. Unmet needs for mental health counseling were not different across age groups (see Table 3).

Medication management. The percentage of receiving medication management increased significantly from early childhood to middle childhood (12–27%; $OR = 2.20$, $p < 0.001$). The difference was also significant between young and older adults (27% vs. 39%; $OR = 1.65, p = 0.017$). Medication management had low percentages of unmet needs (ranging from 5 to 10%) relative to other services across age groups. One group difference was found, where the adolescent group had a slightly higher likelihood of unmet needs for medication management than the middle childhood group (6% vs. 8%; $OR = 0.61, p = 0.004$).

Physical therapy. Physical therapy was mostly used in early childhood and decreased across age groups into young adults, with no significant differences between the adolescence and transition-age adult groups (17% vs. 15%; $OR = 0.85$, $p = 0.243$). The unmet needs for physical therapy were not statistically significant when comparing the younger group to the older group. It was evident that autistic adults had unmet needs for physical therapy that were no different from autistic children and adolescents.

Neurology services. Receipt of neurology services was not significantly different when comparing age groups. Although not statistically significant, there was a relatively higher percentage of older adults using this service than young adults (20% vs. 28%; OR = 1.49, p = 0.072). No age differences were found in the unmet needs for neurology services.

Discussion

In a large statewide sample, the use of most services investigated in this study peaked during early and middle childhood and decreased as individuals aged. The results suggest a realignment of service use and need across the lifespan. We found that the use of therapy services, social skills training, and behavioral/one-on-one support generally declined with age. In contrast, the use of case management, mental health counseling, and medication management increased. Additionally, we found substantial shifts in service use between the adolescents and transition-age adults as well as between transition-age adults and young adults. This is in line with the finding by Turcotte et al. (2016) and past research, which revealed a significant decline in the number of services received following school exit (Roux et al., 2015; Laxman et al., 2019). Lastly, the examination of the age-related variations among adults found that autistic young adults were less likely to use therapy services (i.e., speech/language, occupational, and physical) than transition-age adults. They were also less likely to use case management/support coordination and medication management than older adults.

Children in early and middle childhood used speech/language therapy, occupational therapy, physical therapy, and one-on-one support significantly more than their older counterparts. Addressing language, sensory and motor problems, and behavioral issues at the early stage can be effective (Dimian et al., 2021). The reduced use of these services among adolescents and adults may be indicative of fewer needs associated with autistic traits over time. However, social communication, sensory, and behavioral traits persist for autistic individuals in most cases (Meyer et al., 2018). Given that most intervention-related research focuses on children under age 15 (Wong et al., 2015), there may be limited availability of treatment or service providers for older individuals to meet their changing needs for these therapy services over the lifespan. The higher unmet needs for speech/language therapy and occupational therapy in adolescence, transition-age adults, and young adults also underscores the need for additional research, policy, and programmatic efforts in this area and building capacity of current therapists to provide the support to adults.

While most service types appeared to peak during early and middle childhood, the exceptions were mental health counseling, medication management, and case management. This finding is consistent with previous studies showing the increased use of medications and mental health services with age (Cidav et al., 2013; Rast et al., 2020; Turcotte et al., 2016). This finding is not surprising given that elevated incidence of anxiety and mood disorder, conduct disorders, ADHD, and medical conditions are reported among autistic adults (Buck et al., 2014; Davignon et al., 2018; Mattila et al., 2010). The increased use of medication management across age, especially in older adults, may be associated with the age-related increase in medication use (Esbensen et al., 2009).

We also found that older adults most used case management/support coordination. When comparing to the data in Turcotte et al. (2016), we observed that the rates of receiving case management/support coordination among autistic children and adolescents decreased drastically (Our study: 34%, 33%, 38%; Turcotte et al.: 65%, 65%, 60%). Correspondingly, the unmet needs for support coordination and case management also increased across the two data points. This is concerning because caregivers of children on the autism spectrum often need support with coordinating care (Rast et al., 2020). Access to care coordination also supports parents in engaging in the workforce (Leslie et al., 2017). It may be particularly detrimental for families with the lower socioeconomic status, given that higher caregiver socioeconomic status was associated with parents' knowledge of ASD services and greater ASD service use (Pickard & Ingersoll, 2016). These findings emphasize the need for increasing the availability of case management for autistic individuals from an early age to facilitate timely service access and integrate supports across wide-ranging service needs.

The unmet needs for services were also significant among transition-age and young adults. By examining adult subgroups, findings similar to Turcotte et al. (2016) were that the transition-age adult group was also more likely to report an unmet need for speech/language therapy and social skills training than adolescents. However, our findings diverged from Turcotte et al. (2016) in finding that the unmet need for support coordination/case management was also higher in the transition-age adult group than the adolescent group. Moreover, young adults had higher unmet needs for social skills training, speech/language therapy, and occupation therapy than transition-age adults and higher unmet needs for social skills training and case management/support coordination than older adults. One explanation for the changes is that needed services are no longer available to individuals who age out of the school system and transition-age adults. Substantial percentages of children and adolescents receive services through school systems (Mire et al., 2015). Once individuals on the autism spectrum exit the school-based services system (or after age 21), they no longer receive IDEA-mandated services, such as transition planning, occupational skills, and social skill training (Laxman et al., 2019; Taylor & Henninger, 2015) and must rely upon public health insurance, out-of-pocket pay, and vocational rehabilitation programs for services.

High unmet service needs for various services among transition-age adults to young adults may indicate that the state's policies and programs have not met the lifespan needs of autistic individuals. State-based Medicaid HCBS waiver programs provide services to eligible individuals on the autism spectrum or developmental disabilities in general. HCBS waiver enrollment is associated with increased outpatient visits and decreased unmet healthcare needs among children on the autism spectrum (Leslie et al., 2017; Velott et al., 2016). However, there are substantial differences across states in how individuals are eligible for the waivers, how many receive the waiver, and what services the waiver covers (Ng et al., 2015). For instance, Pennsylvania has two ASD-specific waivers (e.g., the Adult Autism Waiver and the Adult Community Autism Program) and include ASD as a diagnosis that provides entry to HCBS programs (e.g., Community Living Waiver). More than half a million (and 16,532 in Pennsylvania) people with intellectual and developmental disabilities (ID/D), including ASD, are on a waiting list for HCBS waivers (Henry J. Kaiser Family Foundation, 2021), and the average time on a waiting list before enrollment in a waiver targeted to individuals with ID/D is 71 months (Musumeci et al., 2020). A recent study found that over half of autistic adults who were waiting for the Pennsylvania adult autism waiver program had unmet needs for mental health services; three out five had unmet needs for functional skills services (e.g., occupational therapy, speech therapy, and social skill training) and employment support services (Schott et al., 2021).

Autism mandates hold promise for addressing the unmet needs of autistic individuals and increasing access to services (Barry et al., 2017; Mandell et al., 2016). Additional or different benefits may be available under private insurance mandates than Medicaid waivers. However, most private insurance mandates (including private insurance in

Pennsylvania) exclude adults. Given that the majority of the sample in this study was covered by public insurance or both private and public insurance, other factors regarding access to services of the transition-age and young adults may be at play, such as additional needs for access to HCBS waivers, and further research is needed.

Although the current study identified many of the same trends as Turcotte et al. (2016), there were some differences, such as reduced use of speech/language therapy, occupational therapy, social skills training, case management, and medication management across age groups from 2010 to 2018. Moreover, our data showed a broadening need across several areas starting early childhood, including physical therapy, social skills training, mental health counseling, behavioral support, and support coordination. These discrepancies also led to some inconsistent findings between the current study and Turcotte et al.'s (2016) study. For instance, the previous study showed that the adult group had higher unmet needs for one-on-one support than the middle/high school age group. However, the difference was not significant in the current study partially due to a higher proportion of children and adolescents on the autism spectrum reporting unmet needs than the percentage in Turcotte et al. (2016). The reduced service use and increased unmet needs across the two data points indicated that the availability of services is not keeping pace with service needs in type or amount. This trend is likely an urgent need across the U.S., where the ASD prevalence has increased, and individuals continue to age into adulthood and need services even as access to services through the education system ends in early adulthood.

This study also offers a more detailed look at differences among adult age subgroups that are novel. As mentioned, we found that young adults were less likely to use therapy services than transition-age adults. However, they had higher needs for therapy services (except for physical therapy) and social skills training. Also, young adults were less likely to use case management and medication management and also reported higher needs for social skills training and case management than young adults. Further research is needed about the prevalence of ASD in adulthood, clinical trajectories, and outcomes to support autistic adults in getting the services and support they need to increase their quality of life and meet their goals. Adult outcome research will also inform child services as we examine the long-term effect of current child services on the development of autistic people (Robison, 2019). Several efforts have been made to improve the service delivery for autistic adults by expanding funding, research, and treatment. For example, since their first report, the Interagency Autism Coordinating Committee has highlighted the need to improve evidence-based services for adult groups. Along with the increase in the number of projects focused on adults (Cervantes et al., 2021) and the reauthorization of the Autism CARES Act of 2019, more professionals may be trained and subsequently offer treatment to autistic individuals across the lifespan.

Limitations

The strengths of this study include a large and well-characterized sample of people on the autism spectrum. However, some limitations need to be noted. First, the sample was largely homogeneous and comprised primarily of upper-middle-class White families from a single state. This limits the generalizability of findings regarding service use and needs trends among families from more diverse backgrounds and at the national level. More efforts are needed to include racially and ethnically diverse samples across autism research and to describe their service use and experiences as well as unmet service needs (LaClair et al., 2019). Further, our sample is not representative of the entire range of ASD. The rate of ID in our study (17%) was lower than the prevalence of ID in the population of children aged eight years (33%) (Maenner et al., 2020). This may reflect selection bias given that children and adults with severe disabilities are harder to recruit, and families of individuals with complex service needs may have less time and fewer resources to participate in studies.

Second, although our data afforded a unique examination of service use and needs patterns among autistic individuals at different ages, unfortunately, the cross-sectional nature of the data does not allow us to track the same individuals over time to examine how service use and needs change over time within individuals. The age difference found in the current study could be impacted by societal factors, such as service accessibility, treatment research, and state policies and programs. To better understand the age-related impact on service utilization, longitudinal studies would yield a distinct advantage over cross-sectional studies (e.g., Laxman et al., 2019).

Third, dependence on caregiver reports also raises how to best engage autistic adults, especially in the aging population (Volkmar et al., 2014). The reliance on caregiver reports may have two limitations. First, it excluded individuals without caregivers (e.g., aging adults), which limited the generalizability of the findings to aging adults (> 65 years old). Second, caregiver responses may be subject to personal view and recall bias. A recent study showed a significantly higher proportion of caregivers (63% of all caregiver responses) than autistic adults (35% of all adult responses) indicated needs for additional services for autistic adults that were not available (Sandercock et al., 2020). This discrepancy should be addressed in future studies by relying upon direct engagement with autistic adults as well as caregivers to fully understand the service needs of autistic adults and their caregivers.

Last, the sample recruitment was primarily based on Medicaid enrollment and one ASD-associated Medicaid claim. However, the accuracy of ASD in claims data has been examined, and findings suggested acceptable validity of the diagnosis of ASD in the Medicaid claims (e.g., Bickford et al., 2020; Burke et al., 2014). A related limitation was that individuals not receiving Medicaid-funded services, undiagnosed or misdiagnosed population may have been excluded from the study.

Conclusions

By comparing the current use and unmet needs of each service type among autistic individuals who were under 5 years, 6–11 years, 12–17 years, 18–21 years, 22–30 years, and 31 + years, at the time of data collection, we were able to explore age-related service use and needs trends. The current study provides an essential contribution to the literature on service use and needs in the ASD population by replicating and expanding the study of Turcotte et al. (2016) and placing a unique focus on adults. Differences emerged regarding the types of service used and unmet needs for services across ages. Our findings highlighted reductions in service use and increases in unmet services in multiple service areas during the transition to adulthood and among young adults. Compared to the sample almost a decade ago, our study reveals broadening unmet needs among autistic individuals across the lifespan. The availability of ASD-specific services may not be keeping pace with the increased prevalence of ASD. This requires future studies to examine the capacity to provide ASD-specific services (e.g., eligibility criteria, insurance type, service costs) in and outside of the medical and behavioral health service delivery system to meet the needs of all autistic individuals. Our findings regarding the changes in adulthood will need to be replicated and extended with a larger sample using multiple informants in order to capture the voice of autistic adults. Although age does not explain how and why autistic individuals choose a particular service, it provides directions for allocating more resources and reallocating existing resources more effectively and efficiently.

Author Contributions All authors contributed to the study conception and design. Data collection were performed under the supervision of Lindsay Shea. Wei Song performed the statistical analyses. The first draft of the manuscript was written by Wei Song, and all authors provided critical feedback on the previous versions of the manuscript. All authors read and approved the final version for submission and publication.

Funding This work was supported by grant from Eagles Autism Foundation in support of the proposal *Getting Out There: Identifying Individual, Environmental, and Service Use Factors Associated with Community Participation among Adults with Autism Spectrum Disorder*. The Autism Services, Education, Resources, and Training Collaborative (ASERT) Collaborative Eastern Region by the Bureau of Supports for Autism and Special Populations, Pennsylvania Department of Human Services; the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under UJ2MC31073: Maternal and Child Health-Autism Transitions Research Project. This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government.

Declarations

Conflict of interest The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Ethics approval All procedures performed were in line with the principles of the Declaration of Helsinki. The study protocol was approved by the Institutional Review Board of Drexel University.

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

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