



Brief Report: Healthcare Utilization and Expenditure Trends Among Autistic Transition Age Youth

Philip H. Smith¹ · Jonas Ventimiglia¹ · Joe Wright¹ · Jessica E. Rast^{1,2} · Diana E. Schendel¹ · Pricila H. Mullachery³ · Brian K. Lee⁴ · Lindsay L. Shea¹

Received: 20 October 2025 / Accepted: 13 February 2026
© The Author(s) 2026

Abstract

Purpose The transition to adult healthcare is a vulnerable time for individuals with autism spectrum disorder (ASD). Prior research using Medicaid data (2001–2005) found this group had declining utilization rates into adulthood for some types of care (e.g., psychiatric outpatient). Substantial changes to Medicaid and the ASD population have occurred since this time. We reassessed healthcare resource utilization (HCRU) across the transition to adulthood Medicaid claims data from 2015 to 2019.

Methods We selected enrollees with at least one fee for service claim, aged 16–19 years in 2015, who were also enrolled in 2019 using diagnostic groupings: ASD/no ID ($n=23,460$), ID/no ASD ($n=21,256$) and ASD+ID ($n=10,115$). HCRU indicators included utilization rates and per capita expenditures for outpatient, inpatient, long-term, and medication care, with each type further divided into psychiatric and non-psychiatric (i.e., medical).

Results The ID groups had overall higher HCRU than the ASD only group. ASD+ID adults had especially high HCRU for psychiatric outpatient care. HCRU increased into adulthood for psychiatric outpatient and long-term care, driven by higher expenditures among those with >\$0 expenditures. HCRU declined into adulthood for inpatient care and medication use.

Conclusion In contrast to 2001–2005, having an ID diagnosis resulted in greater HCRU across transition to adulthood, potentially reflecting changes in the Medicaid ASD population over time. Consistent with 2001–2005, utilization rates generally declined for all three groups across the transition to adulthood. Greater expenditure among those using psychiatric outpatient and long-term care in adulthood resulted in greater overall resource utilization than adolescence.

Keywords Autism spectrum disorder · Intellectual disability · Medicaid · Young adult · Health expenditures

For autistic youth, aging into adulthood is marked by increasing prevalence of an array of common and impactful physical and mental health conditions, at rates that outpace non-autistic youth (Malow et al., 2023). Simultaneously, the transition to adulthood is often accompanied by challenges

with accessing and utilizing needed healthcare that are disproportionately experienced by autistic individuals given a lack of service and provider availability for this group. For example, autistic youth and their families are less likely to receive transition care planning compared to other children with special health care needs (Cheak-Zamora et al., 2013; Rast et al., 2018). For autistic youth with more intensive support needs, families may be faced with the choice of pursuing power of attorney or guardianship arrangements to support needed care navigation and access processes, yet these processes can be confusing for families and may be unwanted by autistic adults (Roux et al., 2024). Sources of health insurance may change as autistic youth age out of public health insurance services and programs targeted at children with autism specifically or for developmental disabilities, resulting in declines in service access and utilization (Nathenson & Zablotsky, 2017; Shea et al., 2022). In

✉ Philip H. Smith
ps997@drexel.edu

¹ A.J. Drexel Autism Institute, Drexel University, Philadelphia, PA, USA

² Denver Health, Department of Emergency Medicine, Denver, CO, USA

³ Barnett College of Public Health, Temple University, Philadelphia, PA, USA

⁴ Dornsife School of Public Health, Drexel University, Philadelphia, PA, USA

order to improve healthcare outcomes for autistic adults, there is an ongoing need for research that informs evidence-based policies and programs aimed at improving healthcare access across the transition to adulthood.

Medicaid is the most widely utilized source of public health insurance for autistic youth in the U.S. (Shea & Field, 2020). Many autistic youth qualify for Medicaid through the same income-based requirements as the general population; however, Medicaid also provides funding for valuable services to autistic youth and their families through additional mechanisms that may not be income contingent depending on varying state-specific criteria, including subsets of 1915c Home and Community Based Services (HCBS) waivers and 1115 Demonstration waivers. Tracking changes in patterns of healthcare utilization and expenditures across the transition to adulthood among autistic Medicaid enrollees is important for understanding how growing health challenges during this life stage can be better supported by the U.S. healthcare system. Policymakers can use this information to make informed decisions when prioritizing resources and creating or modifying programs to address the changing healthcare landscape for this vulnerable population across the transition to adulthood.

Shea and colleagues published an analysis of autistic Medicaid recipients' healthcare utilization and expenditures as they transitioned to adulthood (Shea et al., 2018). Their analysis found a decline in the percentages with outpatient service claims for youth with autism spectrum disorder (ASD) and intellectual disability (ID) diagnoses as they aged into adulthood, while per capita expenditures among those with any expenditures increased. These results indicated fewer individuals utilizing outpatient services in adulthood, and greater expenditures for those who did use services. Average per capita expenditures among those with any expenditures increased for all services types across the transition to adulthood except for inpatient care (and medical non-psychiatric care for ASD only), potentially reflecting increasing healthcare costs, changes in care fees, or more intensive care among those using services in adulthood.

The findings were based on Medicaid claims data from 2001 to 2005 and there has been a great deal of change in the healthcare policy and program landscape for autistic people since 2001–2005. These changes include Medicaid expansion, greater access to HCBS given directives from the Centers for Medicare and Medicaid Services to prioritize community-based service provision and programs that are intended to enhance access to care coordination across providers and care settings (McLean et al., 2021). Healthcare utilization across the transition to adulthood may have been positively impacted by these changes; for example, Liu and colleagues found HCBS waivers to be associated with reduced emergency care use among autistic youth (Liu

et al., 2022). Further, changes to autism diagnostic criteria, awareness, and access to diagnostic services may have changed the composition of the autism population over time in relation to age of diagnosis and level of support needs.

We aimed to update Shea and colleagues' prior analysis by reassessing healthcare resource utilization (HCRU) across the transition to adulthood, analyzing Medicaid claims data from 2015 to 2019. We estimated overall per capita expenditures, utilization rates, and per capita expenditures among those with >\$0 in expenditures, among those with ASD diagnosis only, ID diagnosis only, and among those with both ASD and ID diagnoses. We examined patterns of HCRU for inpatient care, outpatient care, long-term care, and medication use. For each of these types of care, we further divided HCRU indicators into psychiatric and medical (i.e., non-psychiatric).

Methods

We used national Medicaid Analytic eXtract Files (MAX and Transformed Medicaid Statistical Information System (T-MSIS) Analytic Files (TAF) for analyses. We selected a cohort of individuals aged 16–19 in 2015 who were enrolled in Medicaid in both 2015 and 2019 (aged 20–24). We limited our analysis to 2015–2019 to avoid the impact of period effects related to COVID-19 on longitudinal change in healthcare utilization. We included those enrolled for at least 10 months in a given calendar year to account for administrative churning and in alignment with previous claims-based research focused on autism (Grosse et al., 2022). We selected the claims records for enrollees with ASD or ID using validated algorithms. ASD was identified using 2 outpatient or 1 inpatient claim associated with an ASD diagnosis code (299.xx; F84.x). ID was identified as any use of claims codes 317.xx–391.xx, or F70–F79. Consistent with other published analyses of Medicaid claims data from our study's time period (Bettenhausen et al., 2018), we only included fee for service (FFS) and primary care case management claims (PCCM; managed care plans paid through fee for service). Although the quality of Medicaid comprehensive managed care claim data has improved over time (Samples et al., 2025), there was a temporary and modest decline in quality from 2014 to 2016 as states transitioned from MSIS to T-MSIS systems. Considering that our primary objectives were to examine longitudinal change in healthcare from this time to 2019, and to draw comparisons to prior analyses (2001–2005) that were limited to FFS claims, we limited our analyses to FFS claims.

In Shea and colleagues' (2018) original analysis of 2001–2005 claims data, there were two comparison groups: ASD only and ID only; we added a third group: ASD+ID. The

sizes of each group were ASD only: $N=23,460$; ID only: $N=21,256$; ASD+ID: 10,115. Our primary service type categories were outpatient, inpatient, long-term, and pharmaceutical care. These types are pre-defined in the Medicaid analytic files as described in Table S1 (Christensen et al., 2021). For outpatient, inpatient, and long-term care utilization and expenditures, we distinguished psychiatric care from non-psychiatric (i.e., medical) to be able to draw comparisons to Shea et al. (2018), and because of the high risk for psychiatric conditions among ASD and ID populations (Buckley et al., 2020; Lai et al., 2019). We identified psychiatric care using codes 290.xx-319.xx and F01-F99 (excluding codes for ASD and ID) in any position on the claim, consistent with the approach used by Shea and colleagues. All claims not identified as psychiatric were considered “medical.” Medications were classified as psychiatric using the American Hospital Formulary Service (AHFS) Pharmacologic-Therapeutic Classification©. Drugs categorized within the central nervous system (CNS) agents that fell under the classification of anticonvulsants; psychotherapeutic agents; anxiolytics, sedatives, and hypnotics; antimanic agents; and amphetamines were considered as psychiatric use. A complete list of CNS agents and other medications are available in the AHFS Pharmacologic-Therapeutic Classification©. We defined utilization as at least one claim for a particular type of care during the year of analysis (2015 or 2019). Yearly healthcare expenditures were adjusted for inflation to 2019. We examined both overall per capital expenditures as well as per capita expenditures excluding those with zero expenditures, and Winsorized expenditures within each expense category at the 95th /5th percentile in order to minimize the influence of outliers. The overall expenditures provided a sense of population-wide HCRU, while the expenditures among those with $> \$0$ expenditures provided a better sense of average expenditures among those receiving care. We calculated percent utilizing each service, mean (SD) expenditures, and 25th, 50th, and 75th percentiles for expenditures, for 2015 and 2019. Owing to the substantial sample size, statistical significance testing was not performed; rather, interpretation emphasized clinically meaningful differences. All members of our target population who met inclusion criteria were included in our analysis, and with extremely large sample sizes p-values provide little valuable information. Rather, we interpreted differences between estimates based on their relative size and meaningfulness in the context of prior findings and real-world context.

Results

ASD Only vs. ID Only vs. ASD With ID

Across types of care, indicators of utilization, and the transition to adulthood there was a general pattern where the two groups with ID diagnoses (ID only and ASD+ID) had higher utilization and expenditures than the ASD only group (Tables 1 and 2, and S2). An exception was psychiatric medication use (Table 1): rates of utilization were similar between the ASD only and ID only group; however, in adulthood per capita expenditures among those with $> \$0$ expenditures were greater for ID only than ASD only, resulting in greater overall per capita expenditures. Those in the ASD+ID group had especially high indicators of outpatient HCRU. This difference was most pronounced in adulthood. For example, for overall outpatient care (combined psychiatric and medical) in adulthood, the ASD+ID group’s utilization rate was 87.51%, compared to 78.43% for ID only and 70.79% for ASD only (Table S2). Per capita expenditures for those utilizing services were also substantially higher for the ASD+ID group, resulting in higher overall per capital expenditures for this group (ASD+ID = \$40,081.52; ASD only = \$20,003.25; ID only = \$28,593.49). A closer look at findings broken down by psychiatric (Table 1) vs. medical (Table 2) indicates that this difference was driven primarily by psychiatric care, with medical care utilization indicators more similar between the groups. For all service types, medians and interquartile ranges for expenditures are included in supplementary tables S3-S4.

Longitudinal Change Across the Transition to Adulthood

For all three diagnostic cohorts, overall average per capita expenditures increased for outpatient and long-term care (Tables 1 and 2, and S2). These increasing expenditures were driven by greater expenditures among those with $> \$0$ expenditures, while rates of utilization dropped across the transition to adulthood. In other words, across the transition to adulthood, fewer were utilizing outpatient and long-term care, but average expenditures for those using services increased substantially, resulting in net increases in per capita expenditures. This pattern was consistent when combining psychiatric and medical care (Table S2), as well as when psychiatric and medical care were separated (Tables 1 and 2). For medications, all three indicators of HCRU decreased across the transition to adulthood for all three diagnostic cohorts (Tables 1 and 2, and S2). The pattern for inpatient care was more nuanced. When combining psychiatric and medical care, all three indicators of HCRU decreased for all three groups (Table S2). However, when separating

Table 1 Psychiatric service utilization and expenditures among transition age adolescents with ASD only, ID only, or ASD and ID in 2015 and 2019 Fee for Service Medicaid Claims

	Long-Term Care									
	Inpatient					Medication				
	2015		2019			2015		2019		
	ASD only N=23,460	ASD+ID N=10,115	ID only N=21,256	(change) (N=23,460)		ASD only N=23,460	ASD+ID N=10,115	ID only N=21,256	(change) (N=23,460)	
Inpatient										
Expenditures										
Mean	229.08	632.43	500.92	164.37 (-64.72)		523.67	1082.05	936.31	821.77 (+298.10)	2950.54 (+2014.23)
SD	17.08	29.52	33.23	23.05		29.07	35.13	33.46	31.04	50.65
% utilized	1.85	3.33	3.56	2.54 (+0.69)		1.91	4.62	3.43	1.04 (-0.87)	2.75 (-0.68)
% with > \$0 expenditures	1.74	3.2	3.37	2.12 (+0.38)		1.85	4.57	3.38	1.01 (-0.84)	2.72 (-0.66)
Expenditures (among >\$0)										
Mean	13969.95	20909.04	16038.00	8312.54 (-5657.41)		28864.16	23845.75	28158.24	82389.66 (+53525.50)	108635.10 (+80476.66)
SD	19981.55	33222.03	19952.64	10389.66		37040.07	20112.33	26008.35	92279.79	84330.04
Outpatient										
Expenditures										
Mean	1730.51	3544.01	1879.79	6949.50 (+5218.99)		1244.34	1996.46	1123.43	342.14 (-902.20)	465.74 (-657.69)
SD	58.02	81.19	60.38	109.65		46.78	57.73	44.30	25.38	36.76
% utilized	66.77	81.12	72.07	51.88 (-14.89)		52.6	62.85	45.57	29.36 (-23.24)	28.76 (-16.81)
% with > \$0 expenditures	65.8	80.6	71.39	50.85 (-14.95)		51.71	60.85	44.24	29.12 (-22.59)	28.58 (-15.66)
Expenditures (among >\$0)										
Mean	2653.60	4442.91	2654.91	13744.34 (+11090.74)		2371.88	3188.05	2475.49	1181.53 (-1190.35)	1646.54 (-828.95)
SD	4455.31	6913.24	4344.91	23493.11		4133.07	4133.07	4133.07	2231.71	3195.90

psychiatric from medical care, a unique pattern emerged for psychiatric care, where utilization rates increased (Table 1). These increasing rates were offset by decreasing per capita expenditures among those with >\$0 expenditures, resulting in overall decreases in per capita expenditures for psychiatric inpatient care.

Discussion

This study provides updated estimates of healthcare resource utilization (HCRU) among Medicaid enrollees with ASD or ID diagnoses longitudinally across the transition to adulthood, from 2015 to 2019. Notable patterns emerged from the analyses, including overall higher indicators of HCRU among the two ID groups (ID only and ASD+ID); especially high indicators of HCRU for psychiatric outpatient care among the ASD+ID group in adulthood; and overall declines in service utilization rates and expenditures across the transition to adulthood with two exceptions. First, we found increasing utilization rates for inpatient psychiatric care. Second, we found increasing per capita expenditures for outpatient and long-term care, driven by substantially increasing per capita expenditures among those with >\$0 expenditures, which more than offset declining utilization rates.

This study replicated and extended a prior analysis of the 2001–2005 Medicaid claims data (Shea et al., 2018). There were both similarities and differences when comparing across studies. For example, a key finding from the 2001–2005 data was a decline in psychiatric outpatient service utilization rates across the transition to adulthood for those with ASD or ID diagnoses, accompanied by increasing average expenditures among those utilizing services. This same pattern emerged in the 2015–2019 data. In the 2001–2005 data, the ASD only group tended to have higher utilization rates than the ID only group across psychiatric care types (except for long-term care), while the ID group had greater utilization rates for medical care. In 2015–2019, the ID groups tended to have greater utilization rates across both psychiatric and medical care. A likely explanation for this change over time is the evolution of both ASD and Medicaid. Changes to the ASD diagnostic criteria, increasing numbers of individuals seeking diagnoses (especially in adulthood), and expansion of Medicaid eligibility pathways for those with an ASD diagnosis (e.g., HCBS waivers; general Medicaid expansion) have increased both the prevalence of individuals with an ASD diagnosis and the proportion of these individuals enrolled in Medicaid. This period effect was evident when comparing the sample sizes for our analysis to the earlier study; in 2001–2005 there were 1,637 individuals included in the ASD sample; in

2015–2019 there were 23,460. This increase is consistent with prior work documenting increasing ASD prevalence in Medicaid over time (Rubenstein & Bishop, 2019; Rubenstein et al., 2023). Numbers for ID only also increased, although to a lesser extent. It is also possible these changes resulted from less intensive healthcare support needs in the ASD Medicaid population over time. For example, a prior study of the Wisconsin Medicaid population from 2008 to 2018 found increasing prevalence of ASD in Medicaid claims over time, but declines in number of healthcare visits and amounts paid per year in this population (Rubenstein & Bishop, 2019). Consistent with this interpretation, in comparison to 2001–2005 the 2015–2019 data showed substantially lower utilization rates for psychiatric care across types for the ASD only group. It is also possible that changes in Medicaid eligibility over time have resulted in more ASD only youth and young adults receiving care through managed care or private insurance. Long-term psychiatric care utilization rates decreased substantially between the 2001–2005 and 2015–2019 data, potentially reflecting an overall trend towards de-institutionalization of disabled adults in the U.S. (Larson et al., 2022), and greater access to Home and Community-Based Services (Shea et al., 2021) through Medicaid.

A concerning finding in the 2015–2019 data is that the average per capita cost of psychiatric outpatient care increased substantially for those utilizing services as youth transitioned to adulthood, for all groups and most dramatically for the ASD+ID group. This pattern resulted in overall increases in per capita resource utilization, despite a smaller proportion utilizing services. One possible explanation of this trend is the noted shift away from long-term care for Medicaid-enrolled adults with ID or ASD, resulting in individuals with more intensive mental health care needs utilizing outpatient services. The likelihood that mental health concerns are identified or addressed in the primary care setting has increased significantly over time (Rotenstein et al., 2023). As a result, specialist psychiatric care providers may have seen a proportional increase in visits for more significant mental health concerns, resulting in increased median spending per patient per year. Additional speculative interpretations include greater portions seeking less intensive care through managed care structures or private insurance in adulthood, or increasing expense of adult compared to child psychiatric care.

For both psychiatric and medical care, those with an ID diagnosis (only or with ASD) tended to have higher utilization rates, and utilizers had greater mean expenditures, in comparison to those with an ASD diagnosis only. These differences may reflect more intensive care needs or more expensive care provision among those with an ID diagnosis. For example, autistic adults with an ID diagnosis may

Table 2 Medical (non-psychiatric) service utilization and expenditures among transition age adolescents with ASD only, ID only, or ASD and ID in 2015 and 2019 Fee for Service Medicaid Claims

	Long-Term Care									
	Inpatient					Medication				
	2015		2019			2015		2019		
	ASD only N=23,460	ASD+ID N=10,115	ID only N=21,256	(change) (N=23,460)		ASD only N=23,460	ASD+ID N=10,115	ID only N=21,256	(change) (N=23,460)	
Expenditures										
Mean	218.05	754.16	920.24	33.37 (-184.68)		391.87	3219.28	3277.65	483.52 (+91.64)	1833.58 (-1444.07)
SD	18.46	36.86	40.43	6.35		25.65	59.51	63.62	24.65	45.49
% utilized	2.16	5.19	5.27	0.72 (-1.44)		1.13	5.12	3.99	0.64 (-0.49)	1.65 (-2.34)
% with > \$0	1.89	4.83	4.90	0.58 (-1.31)		1.11	5.05	3.98	0.64 (-0.47)	1.64 (-2.34)
Expenditures (among >\$0)										
Mean	12491.27	16428.00	20075.90	6585.67 (-5906.6)		35925.79	64320.66	83639.52	75549.62 (+39623.83)	111754.70 (+28115.18)
SD	15938.01	23498.49	28884.86	7805.52		45809.27	53870.47	83065.95	94931.57	135678.32
Expenditures										
Mean	6019.21	11940.56	8988.60	5776.13 (-243.08)		673.78	924.64	821.91	211.62 (-462.16)	431.87 (-390.04)
SD	111.39	145.54	134.76	106.12		32.83	38.36	37.18	19.70	28.75
% utilized	84.8	93.28	90.59	58.53 (-26.27)		57.46	66.02	59.60	32.08 (-25.38)	39.99 (-19.61)
% with > \$0	84.39	93.16	90.42	57.08 (-27.31)		43.71	63.88	58.04	31.72 (-11.99)	39.81 (-18.23)
Expenditures (among >\$0)										
Mean	7159.36	12839.65	9960.66	10193.98 (+3034.62)		1182.05	1407.65	1381.12	672.94 (-509.11)	1088.31 (-292.81)
SD	12463.20	18530.65	16649.30	19593.74		4133.07	4133.07	4133.07	1229.42	2080.79

have substantially greater rates of hospital readmission than adults with an autism diagnosis alone (Rast et al. 2025a, b). Specialized inpatient clinics for individuals with ID may be more expensive, and those who receive care in these specialized settings tend to have more complex care needs (Melvin et al., 2022).

Both medication utilization rates and per capita expenditures declined across the transition to adulthood for all three groups, for both psychiatric and medical care. These results contrast with prior findings of increasing medication use across the transition to adulthood among autistic youth and young adults (Davis et al. 2023; Esbensen et al. 2009; Rast et al. 2025a, b; Shea et al. 2019). General declines in medication prescriptions in the Medicaid population or changes in available prescription medications may have contributed to our findings; however, prior studies have still found increased medication use across the transition to adulthood for autistic patients despite these period effects (Davis et al., 2023). It is also possible that increased understanding of the need for behavioral supports as a front line treatment have reduced psychiatric medication use across the transition to adulthood for the Medicaid population; however, we saw both declines in psychiatric and non-psychiatric medication use across all three cohorts. Additional untested hypotheses include greater portions of adults receiving medications through alternative reimbursement sources (e.g., managed care or private insurance), and fewer seeking pharmaceutical care. Considering the deviation from prior findings, these novel trends warrant further exploration from multidisciplinary teams with expertise in Medicaid policy governing medication availability and formulary changes and prescribers.

Additional research has examined healthcare costs and utilization for autistic youth across the transition to adulthood beyond Medicaid. Ames and colleagues reported a cross-sectional study of youth aged 14–25 years old using Kaiser Permanente claims data from 2014 to 2015, which includes individuals across insurers in one region of California (Ames et al., 2021). Autistic youth had higher rates of psychiatric care compared to those with attention deficit hyperactivity disorder and diabetes mellitus across age groups. Notably, outpatient psychiatric care utilization was substantially lower in this private payer population than our estimates from Medicaid enrolled autistic youth. It is unclear whether rates of mental health conditions among autistic youth are more prevalent for those enrolled in Medicaid versus private insurance, although this may be true considering many autistic youth are enrolled in Medicaid through income-based eligibility, and socioeconomic status is broadly associated with mental health conditions (McLaughlin et al., 2012). Further, autistic youth enrolled through disability-related eligibility mechanisms may have

generally more intensive support needs than those who are not enrolled, due to level-of-support criteria utilized in determining eligibility. It is also possible that increased access to mental and behavioral health services for those enrolled in Medicaid drives greater rates of diagnosis and service utilization. Additional research has found that among privately insured autistic individuals during 2000–2013, overall healthcare utilization rates declined across the transition to adulthood (Nathenson & Zablotsky, 2017). We similarly found declines in utilization rates, except for increases in inpatient psychiatric care utilization.

Limitations of our research include that we did not directly test hypothesized mechanisms that may have driven the patterns we observed, as well as differences between our study and Shea and colleagues' earlier parallel analysis. We interpreted longitudinal changes in healthcare utilization and expenditures from 2015 to 2019 to result from the changing age of enrollees across this time-period as they transitioned to adulthood (i.e., age effects). It is possible that period effects that generally influenced Medicaid-funded healthcare from 2015 to 2019 contributed to the patterns that we presented, independent of age; therefore, our findings may not generalize to transition-aged youth beyond the time-period that we studied. We only analyzed claims that were fee for service or primary care case management (PCCM; paid via fee for service) due to varying completeness and quality of comprehensive managed care (CMC) Medicaid claims over our study period. The utilization of managed care through Medicaid has expanded from 2001–2005 to 2015–2019, potentially impacting comparisons to Shea and colleagues' earlier analysis, and limiting the generalizability of our findings. The majority of national Medicaid beneficiaries are currently enrolled through comprehensive managed care (CMC), although rates vary widely state-to-state. Enrollment through CMC is generally substantially lower for those eligible for Medicaid through disability status, potentially limiting impact on the generalizability of our findings. Historically, those with more complex medical needs are more likely to be enrolled through FFS or PCCM, potentially skewing our findings towards more intensive care needs, although in recent years more states are using comprehensive managed care to address complex medical needs among Medicaid enrollees. It will be important for future work to compare FFS versus managed care utilization and expenditures in this population, especially as the quality of managed care data continues to improve and the number of post-COVID-19 years with available data increases. During the study period (2015–2019) Medicaid claims data converted from the MAX to T-MSIS (TAF) system, potentially influencing longitudinal comparisons between 2015 and 2019 data. We limited our years of analysis to 2015–2019 to avoid period effects resulting from the COVID-19

pandemic; it is possible that more updated analyses would demonstrate different trends. We calculated mean expenditure estimates for all within a cohort, as well as the subset that excluded individuals with zero expenditures. We distinguished between types of care, including psychiatric and non-psychiatric care, using the data structure provided by CMS and standard codes; however, there remains the possibility of misclassification.

Consistent with prior analyses of 2001–2005 Medicaid claims data, we continued to identify substantial changes in Medicaid healthcare utilization across the transition to adulthood for youth and young adults with ASD or ID diagnoses. From 2015 to 2019, these changes were marked by greater resource utilization for outpatient and long-term care, driven by greater per capita costs among care utilizers; and reductions in medication and inpatient care resource utilization, driven by both lower utilization rates and lower per capita expenditures among utilizers in adulthood. Further work can help elucidate forces driving these changes, including changes in healthcare funding across the transition to adulthood (e.g., transition from fee for service to comprehensive managed care; acquisition of private insurance sources); changes in care need; changes in care access; and changes in cost of care. There have been extensive efforts to use Medicaid as a mechanism to improve access to care generally and specifically for youth with developmental disabilities, as well as efforts to reduce needs for long-term care utilization over time. In comparison to prior analyses from 2001 to 2005 and consistent with prior work, our findings demonstrate increases in youth and young adults with developmental disability diagnoses in the Medicaid population, especially for ASD. We also found a marked decline in utilization rates for psychiatric long-term care in comparison to the earlier data, potentially representing the impact of de-institutionalization. Further research directly testing these speculative mechanistic interpretations and hypotheses will more fully inform understanding of the reach and impact of relevant policies and programs.

Supplementary Information The online version contains supplementary material available at <https://doi.org/10.1007/s10803-026-07271-x>.

Author Contribution PHS – Conceptualization, Investigation, Methodology, Project administration, Visualization, Writing – original draft; Writing – review and editing JV – Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Project administration, Supervision, Visualization, Writing – review & editing JW – Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Visualization, Writing – original draft, Writing – review & editing JER – Conceptualization, Methodology, Writing – review & editing DES – Conceptualization, Funding acquisition, Methodology, Writing – review & editing PHM – Conceptualization, Methodology, Writing – review & editing BKL – Conceptualization, Methodology, Writing – review & editing LLS – Conceptualization, Funding acquisition, Investigation, Methodology, Project administration, Resources, Super-

vision, Visualization, Writing – review & editing.

Funding This research was supported by the Eunice Kennedy Shriver National Institute of Child Health & Human Development of the National Institutes of Health under Award Number P50HD111142. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health. This project was also supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under cooperative agreements UT6MC45902, Autism Transitions Research Project (ATRP), and UT2MC39440, Autism Intervention Research Network on Physical Health (AIR-P). The information, content, and/or 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. Funders had no role in the design and conduct of the study; the collection, management, analysis, and interpretation of data; preparation or review of the manuscript; or the decision to submit the manuscript for publication. HRSA approved the manuscript prior to submission for publication.

Declarations

Conflict of interest The authors have no competing interests to declare that are relevant to the content of this article.

Open Access This article is licensed under a Creative Commons Attribution 4.0 International License, which permits use, sharing, adaptation, distribution and reproduction in any medium or format, as long as you give appropriate credit to the original author(s) and the source, provide a link to the Creative Commons licence, and indicate if changes were made. The images or other third party material in this article are included in the article's Creative Commons licence, unless indicated otherwise in a credit line to the material. If material is not included in the article's Creative Commons licence and your intended use is not permitted by statutory regulation or exceeds the permitted use, you will need to obtain permission directly from the copyright holder. To view a copy of this licence, visit <http://creativecommons.org/licenses/by/4.0/>.

References

- Ames, J. L., Massolo, M. L., Davignon, M. N., Qian, Y., & Croen, L. A. (2021). Healthcare service utilization and cost among transition-age youth with autism spectrum disorder and other special healthcare needs. *Autism*, 25(3), 705–718. <https://doi.org/10.1177/1362361320931268>
- Bettenhausen, J. L., Richardson, T. E., Shah, S. S., Hall, M., Andrews, A. L., Neff, J. M., Auger, K. A., Hoefgen, E. R., Macy, M. L., Plencner, L. M., & Zima, B. T. (2018). Medicaid expenditures among children with noncomplex chronic diseases. *Pediatrics*, 142(5), e20180286. <https://doi.org/10.1542/peds.2018-0286>
- Buckley, N., Glasson, E. J., Chen, W., Epstein, A., Leonard, H., Skoss, R., Jacoby, P., Blackmore, A. M., Srinivasjois, R., & Bourke, J. (2020). Prevalence estimates of mental health problems in children and adolescents with intellectual disability: A systematic review and meta-analysis. *Australian and New Zealand Journal of Psychiatry*, 54(10), 970–984. <https://doi.org/10.1177/0004867420924101>
- Cheak-Zamora, N. C., Yang, X., Farmer, J. E., & Clark, M. (2013). Disparities in transition planning for youth with autism spectrum disorder. *Pediatrics*, 131(3), 447–454. <https://doi.org/10.1542/peds.2012-1572>

- Christensen, A., Arguello, A., Hula, L., Nguyen, L., Barrett, A., Proctor, K., & Parker, J. (2021). *TAF Technical Documentation: Claims Files*. Available at https://resdac.org/sites/datadocumentation.resdac.org/files/2021-08/TAF_TechGuide_Claims_Files.pdf. Accessed February, 2026.
- Davis, S. A., Annis, I. E., Hughes, P. M., DeJong, N. A., Christian, R. B., Ruble, L. A., & Thomas, K. C. (2023). Patterns of mental health service use during the transition to adulthood among autistic adolescents and young adults. *Autism in Adulthood*, 5(4), 366–373. <https://doi.org/10.1089/aut.2022.0088>
- Esbensen, A. J., Greenberg, J. S., Seltzer, M. M., & Aman, M. G. (2009). A longitudinal investigation of psychotropic and non-psychotropic medication use among adolescents and adults with autism spectrum disorders. *Journal of Autism & Developmental Disorders*, 39(9), 1339–1349. <https://doi.org/10.1007/s10803-009-0750-3>
- Grosse, S. D., Nichols, P., Nyarko, K., Maenner, M., Danielson, M. L., & Shea, L. (2022). Heterogeneity in autism spectrum disorder case-finding algorithms in United States Health administrative database analyses. *Journal of Autism and Developmental Disorders*, 52(9), 4150–4163. <https://doi.org/10.1007/s10803-021-05269-1>
- Lai, M. C., Kassee, C., Besney, R., Bonato, S., Hull, L., Mandy, W., Szatmari, P., & Ameis, S. H. (2019). Prevalence of co-occurring mental health diagnoses in the autism population: A systematic review and meta-analysis. *Lancet Psychiatry*, 6(10), 819–829. [https://doi.org/10.1016/S2215-0366\(19\)30289-5](https://doi.org/10.1016/S2215-0366(19)30289-5)
- Larson, S. A., Neidorf, J., Pettingell, S., & Sowers, M. (2022). *Long-term supports and services for persons with intellectual or developmental disabilities: Status and trends through 2019*. I. o. C. I. University of Minnesota, Residential Information Systems Project. <https://hdl.handle.net/11299/256047>
- Liu, G., Velott, D. L., Kong, L., Dick, A. W., Mandell, D. S., Stein, B. D., Murray, M. J., Ba, D. M., Cidav, Z., & Leslie, D. L. (2022). The association of the Medicaid 1915 (c) home and community-based services waivers with emergency department utilization among youth with autism spectrum disorder. *Journal of Autism and Developmental Disorders*. <https://doi.org/10.1007/s10803-021-05060-2>
- Malow, B. A., Qian, Y., Ames, J. L., Alexeeff, S., & Croen, L. A. (2023). Health conditions in autism: Defining the trajectory from adolescence to early adulthood. *Autism Research*, 16(7), 1437–1449. <https://doi.org/10.1002/aur.2960>
- McLaughlin, K. A., Costello, E. J., Leblanc, W., Sampson, N. A., & Kessler, R. C. (2012). Socioeconomic status and adolescent mental disorders. *American Journal of Public Health*, 102(9), 1742–1750. <https://doi.org/10.2105/ajph.2011.300477>
- McLean, K. J., Hoekstra, A. M., & Bishop, L. (2021). United States Medicaid home and community-based services for people with intellectual and developmental disabilities: A scoping review. *Journal of Applied Research in Intellectual Disabilities*, 34(3), 684–694. <https://doi.org/10.1111/jar.12837>
- Melvin, C. L., Barnoux, M., Alexander, R., Roy, A., Devapriam, J., Blair, R., Tromans, S., Shephstone, L., & Langdon, P. E. (2022). A systematic review of in-patient psychiatric care for people with intellectual disabilities and/or autism: Effectiveness, patient safety and experience. *BJPsych Open*, 8(6), e187. <https://doi.org/10.1192/bjo.2022.571>
- Nathenson, R. A., & Zablotzky, B. (2017). The transition to the adult health care system among youths with autism spectrum disorder. *Psychiatric Services*, 68(7), 735–738. <https://doi.org/10.1176/appi.ps.201600239>
- Rast, J. E., Shattuck, P. T., Roux, A. M., Anderson, K. A., & Kuo, A. (2018). The medical home and health care transition for youth with autism. *Pediatrics*, 141(Suppl 4), S328–s334. <https://doi.org/10.1542/peds.2016-4300J>
- Rast, J. E., Tao, S., Schott, W., Shea, L. L., Brodtkin, E. S., Kerns, C. M., Leonard, C. E., Murray, M. J., & Lee, B. K. (2025a). Psychotropic medication use in children and youth with autism enrolled in medicaid. *Journal of Autism and Developmental Disorders*, 55(1), 258–266. <https://doi.org/10.1007/s10803-023-06182-5>
- Rast, J. E., Wright, J., Voltaire, S., Garfield, T., & Roux, A. M. (2025b). Mental health hospitalization and readmission in autistic adults in a national U.S. sample. *Research in Autism*, 124, 202582. <https://doi.org/10.1016/j.reia.2025.202582>
- Rotenstein, L. S., Edwards, S. T., & Landon, B. E. (2023). Adult primary care physician visits increasingly address mental health concerns. *Health Affairs*, 42(2), 163–171. <https://doi.org/10.1377/hlthaff.2022.00705>
- Roux, A. M., Chvasta, K., McLean, K. J., Carey, M., Perez Liz, G., Tomczuk, L., Lopez, K., Assing-Murray, E., Shattuck, P. T., & Shea, L. L. (2024). Challenges and opportunities in transitioning autistic individuals into adulthood. *Pediatrics*, 154(5), e2024067195. <https://doi.org/10.1542/peds.2024-067195>
- Rubenstein, E., & Bishop, L. (2019). Is the autism boom headed for medicaid? Patterns in the enrollment of autistic adults in Wisconsin Medicaid, 2008–2018. *Autism Research*, 12(10), 1541–1550. <https://doi.org/10.1002/aur.2173>
- Rubenstein, E., Tewolde, S., Michals, A., Fox, M., & Wang, N. (2023). Prevalence of autism among medicaid-enrolled adults. *JAMA Psychiatry*, 80(12), 1284–1287. <https://doi.org/10.1001/jamapsychiatry.2023.3708>
- Samples, H., Lloyd, K., Ryali, R., Martins, S. S., Cerdá, M., Hasin, D., Crystal, S., & Olfson, M. (2025). Completeness and quality of comprehensive managed care data compared with fee-for-service data in National medicaid claims from 2001 to 2019. *Health Services Research*, 60(3), e14429. <https://doi.org/10.1111/1475-6773.14429>
- Schubart, J. R., Camacho, F., & Leslie, D. (2014). Psychotropic medication trends among children and adolescents with autism spectrum disorder in the medicaid program. *Autism*, 18(6), 631–637. <https://doi.org/10.1177/1362361313497537>
- Shea, L., & Field, R. I. (2020). Medicaid coverage for autistic individuals: Coverage, gaps, and research needs. *Drexel Law Review*, 13, 961. https://heinonline.org/HOL/login-hol?redirect_url=https%3A%2F%2Fheinonline.org%2FHOL%2Fmojo%3F%252Fmojo%3D%26auth_token%3DHCMt0qWL8E4AMGB0%252FUMPAJx%252BvtlvC5psIILzYe66ODk%253D%26casa_token%3D%26paywall_url%3D%26referrer%3D%26timestamp%3D1771649443%26url%3D%252FHOL%252FPage%253Fhandle%253Dhein.journals%252Fdrexel13%2526div%253D31%2526id%253D%2526page%253D
- Shea, L., Tao, S., Marcus, S. C., Mandell, D., & Epstein, A. J. (2022). Medicaid disruption among transition-age youth on the autism spectrum. *Medical Care Research and Review*, 79(4), 525–534. <https://doi.org/10.1177/10775587211051185>
- Shea, L. L., Field, R., Xie, M., Marcus, S., Newschaffer, C., & Mandell, D. (2019). Transition-age medicaid coverage for adolescents with autism and adolescents with intellectual disability. *Am J Intellect Dev Disabil*, 124(2), 174–185. <https://doi.org/10.1352/1944-7558-124.2.174>
- Shea, L. L., Miller, K., Verstrete, K. H., Tao, K. S., & Mandell, D. (2021). States' use of medicaid to meet the needs of autistic individuals. *Health Services Research*, 56(6), 1207–1214. <https://doi.org/10.1111/1475-6773.13671>

Shea, L. L., Xie, M., Turcotte, P., Marcus, S., Field, R., Newschaffer, C., & Mandell, D. (2018). Brief report: Service use and associated expenditures among adolescents with autism spectrum disorder transitioning to adulthood. *Journal of Autism and Developmental Disorders*, 48, 3223–3227. <https://doi.org/10.1007/s10803-018-3563-4>

Publisher's Note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.