

Post–High School Service Use Among Young Adults With an Autism Spectrum Disorder

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Objectives: To produce nationally representative population estimates of rates of service use among young adults with an autism spectrum disorder during their first few years after leaving high school and to examine correlates of use.

Design: Nationally representative telephone survey from April 2007 to February 2008.

Setting: United States.

Participants: Parents and guardians of young adults with autism spectrum disorders aged 19 to 23 years.

Main Exposure: Autism spectrum disorder.

Main Outcome Measures: Use of the following services in the prior 2 years or since leaving high school:

mental health services, medical evaluation and assessment, speech therapy, and case management.

Results: Rates of service use ranged from 9.1% for speech therapy to 41.9% for case management; 39.1% of youths with an autism spectrum disorder represented by the survey received no services. The adjusted odds of no services were higher among African American participants and those with low incomes. The adjusted odds of case management were lower among youths with high functional skills and those with low incomes.

Conclusions: Rates of service disengagement are high after exiting high school. Disparities by race and socioeconomic status indicate a need for targeted outreach and services.

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WHAT HAPPENS TO adolescents with autism spectrum disorders (ASDs) once they reach adulthood? The number of young adults in the United States diagnosed as having an ASD is increasing rapidly as ever-larger cohorts of children identified as having an ASD age through adolescence. This trend is especially visible in special education enrollment, where the number of students aged 12 to 17 years classified in the autism eligibility category increased from 15 480 in 1998 to 99 803 in 2007 (**Figure**).¹ It is unclear whether growing enrollment reflects changing identification practices or a true increase in population prevalence.²⁻⁴ Regardless of the root cause, the facts remain that treated prevalence is increasing and that the implications of this trend for service systems are poorly understood.⁵

National, state, and local policy makers have been working hard to meet the needs of the growing numbers of young children identified as having an ASD. Signs of policy activity and resource allocation

to improve services for children with ASDs include national campaigns to educate clinicians about early warning signs, state efforts to cover the costs of early intervention, and the efforts of state commissions and legislative bodies.⁵⁻⁸ However, there has been no effort of a corresponding magnitude to plan for ensuring continuity of supports and services as these children age into adulthood. Likewise, research on services for adults with ASDs is scant relative to the burgeoning literature on children with ASDs.^{9,10}

The majority of an average life span unfolds in adulthood. Life course theory posits that the few years immediately following the age at which students typically exit from high school are a pivotal time for all youths. A positive transition creates a solid foundation for an adaptive adult life course. A negative transition can set the stage for a pathway fraught with developmental, health, and social difficulties.¹¹⁻¹³

Youths with ASDs are especially vulnerable during this period because of their challenges with communication and social interaction, greater reliance on others for aid, and high rates of comorbid

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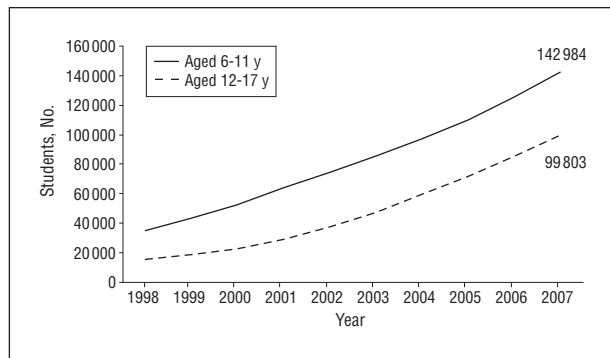


Figure. Number of students enrolled in the special education autism category by age group from 1998 to 2007.¹

health and mental health problems.¹⁴⁻¹⁶ Adolescents who receive special education services face an end of this entitlement as they exit high school. According to the National Institute of Mental Health, “The termination of eligibility and availability of school-based services is particularly problematic for those with disorders that require intensive services that are principally delivered through educational settings, such as youth with autism spectrum disorders.”¹⁷ Thus, service use in the years immediately following high school occurs at a critical developmental period in the context of a shift in the mechanisms through which care is accessed and delivered.

There is a dearth of nationally representative data on the prevalence and correlates of service use among young adults with ASDs. Basic descriptive data on the prevalence and patterns of service use are necessary for planning by policy makers and administrators. Knowledge of the correlates of service use can help identify underserved populations and plan targeted services. If there are significant disparities in rates of service use despite similar levels of need, then new strategies are needed for improving access. Understanding which factors are most strongly related to service use can suggest policy targets that may have the greatest potential leverage for improving access. Lastly, estimates of service use and correlates will help clinicians, service providers, and family members be more informed and better prepared as they try to help teens with ASDs navigate the transition from adolescence to young adulthood.

The aims of this study were to produce nationally representative estimates of rates of service use among young adults with ASDs during their first few years after leaving high school and to examine correlates of use. We focused on 4 services especially salient for youths with ASDs: mental health services, medical evaluation and assessment, speech therapy, and case management. Mental and physical health comorbidities are common in ASDs, with evidence that the risk for some conditions (eg, epilepsy) may actually increase during adolescence and young adulthood.¹⁸ Thus, the need for mental health and medical services tends to be high and ongoing. Language impairment is a core characteristic of ASDs, with many individuals having no ability to speak, and there is a need for continuing support related to communication.¹⁴ Speech therapy is the most commonly received form of service among students with ASDs in high school.¹⁹ By defini-

tion, ASDs are pervasive in impact and affected individuals typically need help from multiple health care and service providers to address various needs. Thus, the need for case management and care coordination is also high in this population. To our knowledge, this is the first article to report such national estimates for the United States.

METHODS

STUDY SAMPLE

Data for this report came from the National Longitudinal Transition Study 2 (NLTS2), a 10-year prospective study being conducted by SRI International for the US Department of Education that is following more than 11 000 youths enrolled in special education as they age into young adulthood. The study included 920 youths enrolled in the special education autism category at the start of data collection in May 2001. Unweighted sample size numbers were rounded to the nearest 10 as required by the data use agreement with the US Department of Education. Analyses for this article are based on data from wave 4, collected from April 2007 to February 2008, which included 680 youths with an ASD. The subset of 410 youths who had exited high school by wave 4 was used as the basis for this article. Use of these data is governed by a data use agreement with the US Department of Education and was approved by the Washington University Institutional Review Board.

The NLTS2 sampling plan was designed to produce a nationally representative sample that would generalize to all special education students who were in 7th through 12th grades or in ungraded programs and who were aged 13 through 16 years on December 1, 2000. A 2-stage process sampled school districts first and then students within districts.²⁰ Determination of a student’s eligibility for special education services in the autism category was made by the school district from whose roster the student was sampled; thus, the sample is subject to some unknown amount of district-to-district variation in eligibility criteria. Of the 1100 sample-eligible students with an ASD, 920 participated in wave 1 for an initial response rate of 83.6%. The 680 participating at wave 4 represented a 73.9% retention rate from wave 1.

Unique weights are included in the data file for each wave of data collection so that estimates generalize to the national population of youths who had been receiving special education services for a given age range and disability type. Weights include adjustment for nonresponse at each wave. Detailed information on the weighting strategy for NLTS2 has been previously published.²¹

Special education enrollment is tracked categorically by type of disability. For the sake of official enrollment reports, each student is counted only once in a primary classification category. Autism is now 1 of 13 primary disability classification categories mandated by the Individuals With Disabilities Education Act after being added in 1990 as part of Public Law 101-476.

Schools do not necessarily use standardized *Diagnostic and Statistical Manual of Mental Disorders* (Fourth Edition) (DSM-IV) diagnostic criteria for assigning a label of autism to children in special education. The US Department of Education’s definition of autism is consistent with DSM-IV criteria but not as specifically detailed. States and districts are left to operationalize the details of diagnostic criteria. Epidemiological research in the United States has found that 99% of children reported in the special education autism category also meet DSM-IV-based criteria for an ASD.^{22,23} Relative to population-based epidemiological ascertainment, the special education autism designation is very specific and moderately sensitive. It is very

unlikely that youths in this enrollment category do not have an ASD, but not all youths with an ASD will be captured by this administrative classification. An unknown proportion of youths with ASDs are enrolled in special education under different primary disability categories such as mental retardation or speech-language impairment. Such youths are not included in the present analyses.

DATA COLLECTION PROCEDURES

The present analyses are based on responses to the wave 4 parent/guardian surveys collected by computer-assisted telephone interviewing. The surveys began with screening to identify the adult most knowledgeable about the youth. Families unavailable by telephone were sent a simplified mail questionnaire and an offer to participate in a drawing for cash and gift incentives. Thirty-five of 410 families (8.5%) received the simplified mail questionnaire.

MEASURES AND VARIABLES

Three dependent variables came from a sequence of questions on service use that began in 1 of 2 ways: "Any time since high school . . ." (for youths who had been in high school during the prior wave of interviews), or "Any time in the past 2 years . . ." (for youths who had already exited high school at the prior wave), ". . . has [youth] received any of the following services?" A list of the following services was then read to respondents: psychological or mental health services or counseling, medical services for diagnosis or evaluation related to his or her disability, and speech or language therapy or communication services. A separate question asked whether the youth had a case manager to coordinate services. We also created an indicator variable if none of the 4 services were received.

Covariates included measures of demographic factors, need and severity indicators, and measures of socioeconomic resources. Age and residential status were included as demographic controls. We included ethnicity and race to be able to identify disparities in service receipt. An indicator for severe language impairment was coded 1 if respondents indicated that a youth "has a lot of trouble speaking clearly" or "doesn't speak at all." We included an indicator for parent-reported diagnosis of attention-deficit/hyperactivity disorder because it is a common comorbidity among those with ASDs.⁸ Unfortunately, the survey did not directly ask parents about other common comorbidities such as intellectual disability. A functional mental skills scale was constructed by summing 4 questions about how well the youth can do the following tasks without help: tell time, read and understand common signs, count change, and look up telephone numbers and use a telephone (each item had 4 response categories: not at all well, not very well, pretty well, or very well). We collapsed the scale into quartiles with higher values corresponding to greater skills. Youths in the highest quartile had values of very well on all 4 constituent indicators. The respondent's household income was used as a measure of family financial resources even though 21.0% of youths were not living with respondents at the time of the interviews. Health insurance status was another measure of resources.

DATA ANALYSIS

Rates of missing data per variable ranged from 0% to 20.7%, with 4 variables missing more than 10.0% (income, 20.7%; functional mental skills, 14.0%; insurance, 13.8%; and residential status, 10.1%) and the remaining variables missing less than 5.0%. Missing data were imputed using sequential regression to create 20 sets of data with no missing values.^{24,25} Standard

methods for analysis of multiply imputed data were used for combining estimates.²⁶

Univariate proportions with 95% confidence intervals were computed for describing the sample. Multivariate logistic regression models estimated the correlates of outcomes. The speech therapy model would not converge because the prevalence was so low. All reported estimates were weighted and variances were adjusted to account for the complex sampling.

RESULTS

Consistent with the higher prevalence of ASDs among males in the general population, the ratio of males to females among youths represented by NLTS2 was 6:1. The mean age was 21.5 years. Measures of impairment and comorbid conditions suggest a range of need for services: 21.2% of youths with an ASD represented by NLTS2 were nonverbal and 34.5% had attention-deficit/hyperactivity disorder (**Table 1**). Most youths lived with their parents (79.0%) and had health insurance (91.5%).

Overall rates of service use were 23.5% for medical services, 35.0% for mental health services, 41.9% for case management, and 9.1% for speech therapy. About two-fifths (39.1%) had not received any of these services.

The adjusted odds of not receiving any services were 3.31 times higher for African American youths compared with white youths and 5.96 times higher for those with incomes of \$25 000 or less compared with those with incomes greater than \$75 000 (**Table 2**). The adjusted odds of no case management were 5.88 times higher among those with incomes of \$25 000 or less compared with those with incomes greater than \$75 000.

Across models, the need indicators of verbal status and attention-deficit/hyperactivity disorder were unrelated to outcomes. Higher functional mental skills were associated with increased odds of no services and reduced odds of case management or medical services.

COMMENT

We reported on the prevalence and correlates of service use among a nationally representative sample of post-high school youths with ASDs. Rates of service use ranged from 9.1% for speech therapy to 41.9% for case management. These rates are lower when compared with estimates for high school students with ASDs from the first wave of the same study, 6 years earlier, when all youths were still in high school: 46.2% received mental health services, 46.9% had medical services, 74.6% were getting speech therapy, and 63.6% had a case manager.¹⁹ The estimates are not perfectly comparable because the post-high school sample does not include all of the youths from the first wave as some had not yet exited school and some were lost to follow-up. Nonetheless, the differences clearly support the general conclusion that exiting high school is associated with a steep decline in service receipt.

Notably, 39.1% of all youths received none of these services. Compared with white youths, the odds of no service use was 3.31 times higher among African American youths despite there being no corresponding disparity when services were examined individually. This height-

Table 1. Characteristics of Youths With Autism Spectrum Disorders No Longer in High School From Wave 4 (2007-2008) of the National Longitudinal Transition Study 2

Variable	Weighted % (95% Confidence Interval)
Demographic factors	
Male	85.8 (79.2-90.6)
Age, y	
19	6.8 (3.5-12.7)
20	17.3 (12.9-22.9)
21	17.9 (13.4-23.6)
22	33.8 (26.0-42.6)
23	24.2 (17.2-32.9)
Hispanic	8.5 (4.9-14.4)
Race	
White	74.8 (66.3-81.8)
African American	16.4 (10.6-24.6)
Other or mixed	8.7 (5.1-14.4)
Residential status	
With parent, guardian, or relative	79.0 (69.8-85.9)
Independent, roommate, dormitory, or barracks	13.1 (7.2-22.7)
Group home or supervised setting	7.9 (4.7-13.1)
Need factors	
Nonverbal	21.2 (14.3-30.3)
Attention-deficit/hyperactivity disorder	34.5 (26.8-43.2)
Functional mental skills, quartile	
1, Very low skills	22.7 (15.4-31.9)
2	21.3 (14.0-30.8)
3	33.1 (24.4-43.1)
4, High skills	22.9 (16.2-31.4)
Resource factors	
Respondent income, \$	
≤25 000	16.7 (10.5-25.0)
25 001-50 000	30.2 (21.0-41.2)
50 001-75 000	35.3 (27.0-44.6)
>75 000	17.8 (12.1-25.5)
Insurance status	
Private	58.6 (48.5-68.1)
Public	30.2 (21.1-41.1)
Uninsured	8.5 (4.7-14.5)
Multiple coverage	2.7 (0.8-7.8)
Dependent variables	
No services	39.1 (30.5-48.5)
Mental health services	35.0 (27.4-43.4)
Medical evaluation and assessment	23.5 (16.5-32.3)
Speech therapy	9.1 (5.8-14.1)
Case management	41.9 (34.0-50.2)

ened risk for total service disengagement among African American youths suggests a need for targeted prevention and outreach. This finding also highlights the importance of examining broad patterns of service disengagement in addition to the use of individual services when devising systems for monitoring service equity as the latter strategy may miss important disparities.

There was no association between need and service use when we examined verbal ability and attention-deficit/hyperactivity disorder. Functional mental skill was the only need factor consistently related with outcomes, with more able youths being less likely to receive case management or medical services and more likely to be receiving no services. The particularly strong link between functional mental skills and case management may be owing to the fact that these services are often pro-

vided for adults via state mental retardation and developmental disabilities departments. Qualifying for adult mental retardation and developmental disabilities services in many states requires demonstrable functional impairment in addition to a diagnostic label. In particular, many Medicaid home- and community-based service waiver programs require a level of care determination that emphasizes functional impairments and self-care skills.

Youths from lower-income households had higher odds of receiving no services at all and of receiving no case management. Multiple factors beyond merely a reduced ability to privately purchase services may be underlying this association. Services may not be located in neighborhoods where poorer families live, and transportation to reach distant services may be expensive or prohibitively time-consuming. Poorer families may also have reduced access to information resources, such as Internet access, where they can learn about available services.

The socioeconomic and racial disparities in service engagement documented in our study clearly indicate a need for further research into access barriers, the development and evaluation of equitable service delivery models, and targeted policies to promote access among underserved populations. The Interagency Autism Coordinating Committee is responsible for establishing autism research priorities and updating them annually. The 2010 report had 2 sections of recommendations for research related to services and adults; however, no explicit mention was made of addressing racial or socioeconomic disparities in service use among adults.²⁷ We recommend that future revisions of Interagency Autism Coordinating Committee research priorities include explicit calls for investigating racial and socioeconomic disparities in service access and individual outcomes among adults with ASDs.

This study has some limitations. First, the sample is representative of youths who had been enrolled in the special education autism category at baseline and may not be fully representative of all youths with an ASD in the general population in so far as some may be served in other special education categories. Second, respondents' knowledge and recollection of service use and related factors may not be perfect. The use of self-report to measure health care utilization may lead to underreporting, the most common problem with this form of data collection.²⁸ If it were feasible, direct examination of health and services records might yield different prevalence estimates. Unfortunately, there was no way of verifying the reports of respondents by checking medical records. Third, the study does not include an indicator for state location, precluding the potential analysis of important state-to-state differences in policies that can influence service use and related outcomes.^{5,29-31} Finally, these are cross-sectional associations and therefore causal attributions are not possible. Once all of the NLTS2 youths have exited high school and the data become available, future research should examine longitudinal trajectories of service use to discover risk factors for service discontinuity.

Several strengths of the study counterbalance its limitations. First, the national representativeness of the sampling design makes findings highly generalizable and relevant for policy and practice. Second, in contrast to most prior research in the United States, the size and diver-

Table 2. Logistic Regression Models Predicting Post-High School Use of Services Among Young Adults With Autism Spectrum Disorders From Wave 4 (2007-2008) of the National Longitudinal Transition Study 2

Variable	Odds Ratio (95% Confidence Interval)			
	No Services	Case Management	Mental Health Services	Medical Evaluation and Assessment
Demographic factors				
Female	0.47 (0.11-1.94)	2.02 (0.65-6.30)	1.81 (0.54-6.03)	0.95 (0.28-3.25)
Age, y				
19	1 [Reference]	1 [Reference]	1 [Reference]	1 [Reference]
20	0.50 (0.13-1.88)	1.63 (0.38-6.96)	1.22 (0.35-4.29)	1.89 (0.37-9.68)
21	0.37 (0.09-1.47)	1.87 (0.45-7.78)	0.78 (0.23-2.70)	1.96 (0.35-10.83)
22	0.37 (0.09-1.54)	2.28 (0.50-10.31)	1.12 (0.32-3.91)	1.28 (0.26-6.42)
23	0.89 (0.19-4.08)	1.23 (0.23-6.55)	0.60 (0.13-2.71)	3.39 (0.58-19.71)
Hispanic				
1.33 (0.41-4.31)	0.75 (0.24-2.29)	2.39 (0.67-8.56)	0.41 (0.10-1.68)	
Race				
White	1 [Reference]	1 [Reference]	1 [Reference]	1 [Reference]
African American	3.31 (1.29-8.48)	0.73 (0.26-2.02)	0.53 (0.23-1.23)	0.58 (0.19-1.79)
Other or mixed	1.30 (0.29-5.81)	1.01 (0.28-3.66)	0.30 (0.06-1.40)	0.34 (0.09-1.24)
Residential status				
With parent, guardian, or relative	1 [Reference]	1 [Reference]	1 [Reference]	1 [Reference]
Independent, roommate, dormitory, or barracks	2.85 (0.66-12.35)	0.14 (0.03-0.61)	0.83 (0.22-3.11)	0.22 (0.04-1.23)
Group home or supervised setting	2.76 (0.59-12.98)	0.80 (0.20-3.20)	1.37 (0.35-5.39)	0.44 (0.14-1.41)
Need factors				
Nonverbal	1.30 (0.44-3.88)	0.86 (0.33-2.27)	0.56 (0.20-1.55)	1.42 (0.50-4.09)
Attention-deficit/hyperactivity disorder	1.01 (0.46-2.24)	0.99 (0.51-1.95)	1.27 (0.66-2.44)	1.04 (0.51-2.12)
Functional mental skills, quartile				
1, Very low skills	1 [Reference]	1 [Reference]	1 [Reference]	1 [Reference]
2	3.79 (0.77-18.62)	0.22 (0.06-0.77)	0.43 (0.13-1.40)	0.26 (0.08-0.85)
3	4.70 (1.00-22.19)	0.25 (0.07-0.83)	0.66 (0.21-2.13)	0.29 (0.09-0.92)
4, High skills	1.86 (0.38-8.95)	0.22 (0.07-0.76)	1.21 (0.40-3.68)	0.41 (0.11-1.48)
Resource factors				
Respondent income, \$				
≤25 000	5.96 (1.20-29.66)	0.17 (0.04-0.67)	0.71 (0.21-2.40)	0.75 (0.18-3.15)
25 001-50 000	2.92 (0.91-9.39)	0.42 (0.14-1.28)	0.74 (0.26-2.13)	0.92 (0.32-2.68)
50 001-75 000	1.86 (0.66-5.27)	0.47 (0.18-1.21)	1.45 (0.58-3.68)	1.13 (0.42-3.06)
>75 000	1 [Reference]	1 [Reference]	1 [Reference]	1 [Reference]
Insurance				
Private	1 [Reference]	1 [Reference]	1 [Reference]	1 [Reference]
Public	0.45 (0.11-1.88)	1.19 (0.41-3.47)	1.81 (0.68-4.82)	2.38 (0.79-7.15)
Uninsured	2.49 (0.54-11.36)	0.34 (0.06-2.12)	0.50 (0.10-2.47)	1.01 (0.22-4.56)
Multiple coverage	0.79 (0.03-19.82)	3.89 (0.18-84.13)	1.80 (0.15-21.53)	5.53 (0.34-90.04)

sity of the sample allowed us to examine disparities in service use by demographic factors including ethnicity, race, and socioeconomic status. Third, the data are very recent and present an up-to-date picture as compared with the handful of extant studies of young adults with ASDs, many of which were performed more than a decade ago.

The number of youths in the United States diagnosed as having an ASD and entering young adulthood will continue to rise in the foreseeable future. The National Institutes of Health Strategic Plan for Autism Research has flagged research on services and adulthood as deserving increased attention. This study represents an important step in the process of building a foundation of evidence that can help improve services and foster independence and health among youths with ASDs.

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If the person you are talking to doesn't appear to be listening, be patient. It may simply be that he has a small piece of fluff in his ear.
—Winnie the Pooh