



NTACT

National Technical Assistance Center on Transition

Summary of National Reports on Secondary Transition and Students with Autism Spectrum Disorder

What is Autism Spectrum Disorder?

Students with autism spectrum disorder (ASD) are youth who have hopes and dreams for a happy, successful life after school. They reflect a constellation of preferences, interests, strengths, and experiences. Youth with ASD are, like youth without disabilities, individuals first.

ASD is a neurodevelopmental disorder characterized by difficulties with social interactions, communication, and restricted, repetitive behaviors, interests, and activities (American Psychiatric Association, 2013). Additional associated characteristics, include intellectual impairment, sensory sensitivity, attention and executive functioning problems, motor difficulties, and behavior problems (Johnson, 2007). As the term “spectrum” implies, ASD presents differently in every individual diagnosed with the disability, resulting in unique strengths and differences.

Approximately 1 in 59 children has been identified as having ASD according to the Center for Disease Control and Prevention’s Autism and Developmental Disabilities Monitoring Network (Baio et al., 2018). The number of children nationwide identified as having ASD rose 165% between the 2005-2006 and 2014-2015 school year (Samuels, 2016). In 2016, 578,099 children ages 6-21 received special education services under the Individuals with Disabilities Education Act (IDEA), Part B (IDEA Data Center, 2018).

Where Are We Now?

Many youth with ASD are successfully participating in college, career, and community in valued ways. However, some youth with ASD experience many challenges as they transition from school to adulthood. Untimely transition planning, complex adult service systems, and lack of job opportunities are only a few factors that influence the post-school success of this population (Roux, Shattuck, Rast, Rava, & Anderson, 2015). Considering the poor post-school outcomes of youth with ASD, there is a critical need for policy makers, researchers, school personnel, and families to be aware of the current status of this population. The following sections summarize the most recent reports from the Government Accountability Office, A. J. Drexel Autism Institute’s Life Course Outcomes Program, the Institute of Education Science, National Center on Special Education Research, and the U.S. Department of Health and Human Services 2017 Report to Congress regarding secondary transition for youth with ASD.

Government Accountability Office

During the 2015-16 school year, the Government Accountability Office (GAO) reviewed relevant federal laws and regulations and conducted a nationwide survey of district-level special education directors to determine information about the services provided to youth with ASD. Specifically, the GAO examined (a) services and supports provided, (b) key challenges to successful transition, and (c) extent to which federal agencies have collaborated to assist with transition youth with ASD, protected under IDEA provision, as they transition to adulthood. Their findings indicated:

- In the 2015-16 school year, of the 588 school districts surveyed, approximately 85% provided transition-age youth with ASD instruction in life, social, and behavioral skills.
 - Instruction in self-advocacy (87%), social (86%), and organizational (86%) skills were provided by the most districts.
- Services provided were influenced by factors such as size and poverty level of district.
- Beginning transition planning earlier than when youth with ASD turn 16 has many benefits.
- About 32% of school districts begin transition planning when students are older than 14.
- The Autism Collaboration, Accountability, Research, Education, and Support Act of 2014 calls for Department of Health and Human Services' (HHS) Interagency Autism Coordinating Committee (IACC) to include in its strategic plan, as practical, services for individuals with ASD.
 - However, HHS has not regularly engaged federal agencies (that are not members of IACC) that provide services or financial assistance to transition-age youth with ASD, such as the Departments of Labor and Housing and Urban Development.
- Recommendations to federal agencies made by the GAO included:
 - Department of Education should investigate the benefits/implications of amending IDEA to require earlier transition planning
 - HHS should encourage collaboration with non-IACC member agencies

The complete report can be accessed at: <https://www.gao.gov/products/GAO-17-352>

National Autism Indicators

The National Autism Indicators (NAI) Report is a publication series produced by the A.J. Drexel Autism Institute's Life Course Outcomes Program. The Life Course Outcomes Program strives to build a base of knowledge about things other than clinical interventions that promote positive outcomes for people on the autism spectrum and their families and communities.

2015 National Autism Indicators Report: Transition into Young Adulthood (Roux et al., 2015)

The 2015 National Autism Indicators Report: Transition into Young Adulthood examined 12 services youth with ASD commonly use (i.e., speech-language therapy, occupational/life skills therapy, physical therapy, vocational services, diagnostic medical services, psychological/mental health/social work, transportation, assistive technology/devices, personal assistant, in-home/classroom aide, respite care, case management).

- Nearly all youth (97%) received at least one of these 12 services while in high school with service usage dropping sharply following high school.
- In their early 20s, 37% of youth were defined as “disconnected” (i.e., neither worked outside the home nor continued education after high school).
- 28% of youth were neither employed nor attending postsecondary school or training and were receiving no services or supports.

Demographic data from this report are consistent with data from the National Longitudinal Transition Study-2012 data. Specifically, middle and high school youth with ASD, when compared to all students receiving special education and related services under IDEA, are significantly:

- More likely to be male (84% versus 67%);
- More likely to have at least one parent with a four-year college degree (43% versus 26%) and parents who are married (72% versus 63%).
- More likely to have a co-occurring chronic health or mental health condition (43% versus 28%);
- More likely to experience challenges communicating (50% versus 29%);
- Less likely to be from socioeconomically disadvantaged families (37% versus 58%);
- Less likely to be Black not Hispanic (12% to 19%) or Hispanic (16% versus 24%);
- Less likely to be able to manage independently and develop friendships:
- Less likely to independently manage activities of daily living (17% versus 46%);
- Less likely to know how to make friends (76% versus 92%);
- Less likely to report getting together with friends weekly (29 % versus 52%).
- Less likely to be given at least some input into IEP and transition planning (4 % to 59%);
- Less likely to have taken a college entrance or placement test (29% to 42%); and
- Less likely to have paid work experiences in the past year (23% to 40%).

The complete report can be accessed at: <https://drexel.edu/autismoutcomes/publications-and-reports/publications/National-Autism-Indicators-Report-Transition-to-Adulthood/>

2016 National Autism Indicators Report: Vocational Rehabilitation (Roux, Rast, Anderson, & Shattuck, 2016)

Note: These are national-level statistics; state-level statistics vary widely and can be found in the full report

- Not everyone with ASD who applies to Vocational Rehabilitation (VR) gets services.
 - About two-thirds do, while others refuse services or cannot be contacted.

- Some states do not have enough funding to serve everyone who is eligible for services, so they focus on serving those with the most significant disabilities.
- It is not known what happens to the one-third who do not get services.
- About 60% of people with ASD who use VR services leave with a job; about the same rate as those with intellectual disability or other types of disabilities.
- About 80% of those with ASD work part-time at a median weekly rate of \$160. These earnings place most workers with ASD below the federal poverty line.
- About one-third of workers with ASD use supported employment, however:
 - VR no longer pays for supported employment services once people leave VR.
 - Extended supports may be available but not through VR dollars.
 - There are no data on what happens to people after they leave VR.

The complete report can be accessed at: <https://drexel.edu/autismoutcomes/publications-and-reports/publications/National-Autism-Indicators-Report-Vocational-Rehabilitation/>

2017 National Autism Indicators Report: Developmental Disability Services and Outcomes in Adulthood (Roux Shattuck, Rast, & Anderson, 2017)

- Findings describe the 3,520 working-age adults (18-64 years) with ASD, who were no longer in high school, and were using DD services when they participated in the 2014-2015 ACS survey between July 1, 2014, and June 30, 2015.
 - This is a particular subset of individuals with ASD who received state-funded services.
- The Adult Consumer Survey (ACS) is part of the National Core Indicators (NCI) -a collaboration of the National Association of State Directors of Developmental Disabilities Services and the Human Services Research Institute.
- Data were collected through review of state documents, interviews with people who received DD services, and/or interviews with someone who knew the person well if needed.
- The ACS is not a nationally representative survey of all adults with ASD. Findings cannot be used to make inferences to the general population of individuals on the autism spectrum

Population Characteristics:

- Mean age was 34 years; eight years younger than DD service users who did not have ASD.
- Half (51%) of middle-aged adults (45-64 years) with ASD had severe or profound intellectual disability (ID), compared to only 16% of young adults (18-24 years) with ASD.
- In some states all adults with ASD also had ID, while in other states approximately half had ID -likely reflecting differences in state policy about who qualifies for DD services.

- Younger adults with ASD were more likely to use spoken language as their primary means of expression than middle-aged adults with ASD.

Outcomes for Adults with ASD (ages 18-64) who received DD services:

DD Service Access:

- 25% reported not receiving services they felt they needed
- 51% received respite care if they lived in the home of a parent/relative
- Average number of services funded by state or county agencies was 6 from a list of 13

Health and Mental Health:

- 51% had at least one additional health condition from a list of 11 common conditions
- 54% had anxiety, mood disorder, psychotic disorder or other mental health/psychiatric condition in addition to ASD
- 64% took medication for either mood disorder, anxiety, and/or psychotic disorder and/or behavioral challenges

Employment and Other Day Activities:

- 14% worked in the community for pay in settings that also employed people without disabilities
- 42% participated in unpaid activities in facilities with others with disabilities (sometimes called day programs)
- 27% had no work or activities in the previous two weeks in community or facility-based settings

Living Arrangements:

- 49% lived in the home of parents or other relatives. Of these, 81% had been there over 5 years
- 27% lived in a group homes consisting of 1 to 15 people with disabilities; 31% of these were in 1-3 person homes
- 38% of those who lived with parents or relatives received no paid in-home supports

Social and Community Participation:

- 80% shopped or dined out or did errands in the community at least once a month
- 72% of the subset of adults who could self-report answers to questions said they had a friend who was not a family member or staff person
- 43% made their own choices about when to get up, when to eat, and when to go to sleep
- 40% chose what to do with their spending money

Independence and Rights:

- 53% had a court-appointed guardian on a limited or full basis
- 74% could be alone with friends of visitors in their home

Knowledge gaps and future research priorities:

- There were many discrepancies between what we know from other research versus the statistics derived from the Adult Consumer Survey (ACS) data.
- Very little is known about which types of DD services work best for whom, or which related state policies result in the best outcomes.
- It is difficult to reconcile the ACS statistics about high levels of services satisfaction with anecdotal reports to the contrary

The complete report can be accessed at: <https://drexel.edu/autismoutcomes/publications-and-reports/publications/National-Autism-Indicators-Report-Developmental-Disability-Services-and-Outcomes-in-Adulthood/>

National Longitudinal Transition Survey-2

The National Longitudinal Transition Study-2 (NLTS2), a project sponsored by the United States Department of Education, provided information about youth with disabilities over a 10-year period using a nationally representative sample of secondary students with disabilities. The report documented the experiences of a national sample of students who were 13 to 16 years of age in 2000 as they moved from secondary school into adult roles. They were 21 to 25 years old at the final data collection in 2009.

- Up to eight years after high school, only 43.9% of individuals with ASD were enrolled in a postsecondary education program (compared to 67% of all individuals with disabilities).
- Up to 8 years after high school, only 63.2% of individuals with ASD had been employed at some point since high school (compared to about 91% of all individuals with disabilities).
- Only 17% of individuals with ASD lived independently (compared to 45% of all individuals with disabilities).
- Twenty-two percent of youth with ASD reported not feeling as if they had much personal autonomy. This percentage is significantly lower than same age peers without disabilities.

Summary from Newman et al. (2011); the complete report can be accessed at: <https://ies.ed.gov/ncser/projects/nlts2/>

National Longitudinal Transition Survey 2012

The National Longitudinal Transition Survey 2012 (NLTS 2012), a project sponsored by the United States Department of Education, studied the high school experiences of transition-age youth. Students, parents, teachers, and principals were asked to take part. NLTS 2012 collected information from approximately 13,000 students, ages 13 to 21, from more than 400 school districts. Wave 1 of data collection for NLTS 2012 began in spring 2012 and continued through summer 2013, and wave 2 began in spring 2014. This report included 1,080 (about 8% of all respondents) youth with ASD (Lipscomb et al., 2017).

In comparison to other youth with an IEP:

- Youth with ASD and intellectual disability showed less self-determination than youth with an IEP.
- Youth with ASD were less likely to engage in activities that demonstrate their autonomy
- Youth with ASD were less likely to report choosing activities to do with friends, communicating with friends and family, and planning weekend activities they like to do
 - For example, 45% of youth with ASD chose activities to do with friends at least most of the time, compared with 56% of youth with an IEP overall
- Youth with ASD were less likely to pursue two additional activities: going to movies, concerts, and dances, and volunteering in activities of interest
- Youth with ASD reported a weaker sense of self-direction than youth with an IEP overall on 5 of 14 items in the survey

About 90% of youth across nearly all the disability groups report positive views about their self-direction. The biggest difference for youth with ASD relative to all youth with an IEP was in terms of being able to make friends in new situations (67% versus 86%)

Youth with ASD attended and completed postsecondary education programs at lower rates, experience lower rates of employment, earn less money, work fewer hours, are less engaged in their communities, and live independently less often than their peers without disabilities. For example:

- Only 43.9% of youth with ASD ever attended any type of postsecondary education (i.e., 2-year or community colleges, vocational, business, or technical schools, 4-year colleges or universities) compared to 67.4% of youth without disabilities.
- Only 37.2% of individuals with ASD were employed compared to 66.1% of their peers without disabilities.
- Youth with ASD had less paid work experience in the past year compared to their peers with other disabilities (23% vs. 40%).
- Youth with ASD struggled more with daily living skills than their peers in other disability categories.

- Only 17% of youth with ASD performed daily living activities well compared to an average of 46% of youth in other disability categories.
- Parents of youth with ASD had lower expectations of them living independently by the age of 30 compared to parents of youth with other disabilities (49% vs. 78%).

The NLTS 2012 report also provides updated information about how the characteristics and experiences of youth in special education have changed over time (Liu et al., 2018). Most of the analyses examine trends for in-school youth ages 15 to 18 from 2003 to 2012, using the NLTS2 and NLTS 2012. When comparable data are available from the NLTS, the volume also examines trends starting in 1987 for youth ages 15 to 18 and youth ages 19 to 21 who were still enrolled in high school. Overall, the number of youth with ASD with an IEP grew 379% between 2003 to 2012.

Statistically significant findings:

The following percentages increased for youth (ages 15-18) with ASD from 2003-2012:

- Living in households in which no parent had a paid job (9% to 17%)
- Living in households that received Supplemental Nutrition Assistance Program benefits in the past two years (6% to 17%)
- Had any trouble understanding what other people say (78% to 70%)
- Agree a lot they are part of the school (25% to 53%)
- Participated in a school or out-of-school club or sports team (51% to 75%)
- Participated in an out-of-school club or sports team (30% to 58%)
- Received services from a tutor at school (12% to 27%)
- Received psychological or mental health counseling services at school (16% to 34%)
- Parent attended a parent-teacher conference increased (78% to 87%)
- Had a school-sponsored work activity in the past year (11% to 21%)

The following percentages decreased for youth (ages 15-18) with ASD from 2003-2012:

- Parent helped with homework at least once a week (60% to 48%)
- Parent met with school staff to develop transition plans (78% to 65%)
- Had trouble communicating (64% to 52%)

Important findings (but not statistically significant):

- Provided at least some input in IEP and transition planning increased (32% to 41%)
- Performed all five daily living activities without help at least pretty well or usually decreased (21% to 5%)
- Had an allowance or other money they can decide how to spend (73% to 62%)
- Had a savings or checking account decreased (65% to 51%)

- Teased or called names at school decreased (66% to 38%)
- Met with school staff to develop transition plans decreased from (75% to 63%)
- Currently had a job decreased (7% to 6%)

The complete report can be accessed at:

https://ies.ed.gov/ncee/projects/evaluation/disabilities_nlts2012.asp

2017 Report to Congress: Young Adults and Transitioning Youth with Autism Spectrum Disorder

The U.S. Department of Health and Human Services compiled a report to Congress as mandated by the Autism CARES Act of 2014 (P.L. 113-157). The report describes the challenges related to transitioning from school-based services to services available during adulthood for individuals with ASD. A major finding of the report is that there are very few federal resources specifically targeting youth and young adults with ASD transitioning to adulthood.

Recommendations for individuals with ASD as they transition to adulthood include a need to:

- design, develop, evaluate, and implement cohesive programs that enable delivery of services in a coordinated, comprehensive, and individualized manner;
- research and test the efficacy of new and existing service and support models that are designed to improve outcomes for youth and young adults with ASD;
- address the integration of funding sources, outcomes research, surveillance, and services among and across those offered to youth in the educational system and those provided to adults in the health care and social services systems;
- increase access to, and the quality of, services and supports;
- assure the health, well-being, and full integration into community life of youth and young adults with ASD;
- increase provider training and public acceptance of the neurodevelopmental differences and strengths associated with ASD; and
- alleviate the growing burden of navigating multiple systems for individuals with ASD and their families.

The complete report can be accessed at: <https://iacc.hhs.gov/publications/report-to-congress/2017/>

References

- American Psychiatric Association (2013). *The diagnostic and statistical manual of mental disorders (5th ed.)*. Arlington, VA: American Psychiatric Publishing.
- Anohina, A. (2005). Analysis of the terminology used in the field of virtual learning. *Journal of Educational Technology & Society*, 8, 91-102.
- Baio, J., Wiggins, L., Christensen, D.L., Maenner, M. J., Daniels, J., Warren, Z., ... Durkin, M.S. (2018). Prevalence of autism spectrum disorder among children aged 8 years: *Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2014. Morbidity and Mortality Weekly Report: Surveillance Summaries*, 63(2), 1-21. Retrieved from https://www.cdc.gov/mmwr/volumes/67/ss/ss6706a1.htm?s_cid=ss6706a1_w
- IDEA Data Center, Retrieved from: <https://ideadata.org/interactive-public-reporting-engine-v2>.
- Johnson, C. P., Myers, S. M., & the Council on Children with Disabilities. (2007). Identification and evaluation of children with autism spectrum disorders. *Pediatrics*, 120, 1183-1215. doi:10.1542/peds.2007-2361
- Lipscomb, S., Haimson, J., Liu, A.Y., Burghardt, J., Johnson, D.R., & Thurlow, M.L. (2017). *Preparing for life after high school: The characteristics and experiences of youth in special education. Findings from the National Longitudinal Transition Study 2012. Volume 2: Comparisons across disability groups: Full report* (NCEE 2017-4018). Washington, DC: U.S. Department of Education, Institute of Education Sciences, National Center for Education Evaluation and Regional Assistance.
- Liu, A. Y., Lacoë, J., Lipscomb, S., Haimson, J., Johnson, D. R., & Thurlow, M. L. (2018). *Preparing for life after high school: The characteristics and experiences of youth in special education. Findings from the National Longitudinal Transition Study 2012. Volume 3: Comparisons over time (Full report)* (NCEE 2018-4007). Washington, DC: U.S. Department of Education, Institute of Education Sciences, National Center for Education Evaluation and Regional Assistance. Available at https://ies.ed.gov/ncee/projects/evaluation/disabilities_nlts2012.asp
- Newman, L., Wagner, M., Knokey, A.-M., Marder, C., Nagle, K., Shaver, D., Wei, X., with Cameto, R., Contreras, E., Ferguson, K., Greene, S., and Swarting, M. (2011). *The post-high school outcomes of young adults with disabilities up to 8 years after high school. A report from the National Longitudinal Transition Study-2 (NLTS2)* (NCSE 2011-3005). Menlo Park, CA: SRI International. Available at www.nlts2.org/reports/
- Roux, A.M., Shattuck, P.T., Rast, J.E., Rava, J.A., & Anderson, K.A. (2015)

National autism indicators report: Transition into young adulthood. Philadelphia, PA: Life Course Outcomes Research Program, A.J. Drexel Autism Institute, Drexel University.

Roux, A.M., Rast, J.E., Anderson, K.A., and Shattuck, P.T. . (2016). *National autism indicators report: Vocational rehabilitation.* Philadelphia, PA: Life Course Outcomes Research Program, A.J. Drexel Autism Institute, Drexel University.

Roux, A.M., Shattuck, P.T., Rast, J.E., Anderson, K.A. (2017). *National autism indicators report: Developmental disability services and outcomes in adulthood.* Philadelphia, PA: Life Course Outcomes Research Program, A.J. Drexel Autism Institute, Drexel University.

Samuels, C. A. (2016). Number of U.S. students in special education ticks upward. *Education Week*. Retrieved from <http://www.edweek.org/ew/articles/2016/04/20/number-of-usstudents-in-special-education.html>