

AUCD Summary and Analysis:

[Young Adults and Transitioning Youth with Autism Spectrum Disorder](#)

In September 2017, the U.S. Department of Health and Human Services publicly released a report to Congress focusing on young adults and transition-age youth with autism spectrum disorder (ASD), as mandated by the [Autism CARES Act of 2014](#). The report summarizes existing federal initiatives (across agencies) focused on transition and identifies gaps in research, programs, and services. AUCD has developed this abbreviated summary of key findings as a resource for the LEND and DBP networks.

Part 1. Background The report begins by establishing a basic understanding of ASD and the target population. These summaries are based heavily on the following source material:

Datasets

- [National Survey of Children's Health \(NSCH\)](#)
- [National Survey of Children with Special Health Care Needs \(NS-CSHCN\)](#)
- [National Health Interview Survey \(NHIS\)](#)
- [National Longitudinal Transition Study 2012 \(NLTS 2012\)](#)
- [National Longitudinal Transition Study-2 \(NLTS2\)](#)

Analyses

- [Autism and Developmental Disabilities Monitoring \(ADDM\) Network](#)
- [2017 National Autism Indicators Report](#)
- [2015 National Autism Indicators Report: Transition into Young Adulthood](#)
- [Interagency Autism Coordinating Committee \(IACC\) 2016 Strategic Plan](#)
- [IACC ASD Research Portfolio Analysis Report](#)
- 2017 Government Accountability Office (GAO) report: [Youth with Autism: Roundtable Views of Services Needed During the Transition into Adulthood \(GAO-17-109\)](#)
- [Students with Disabilities: Better Federal Coordination Could Lessen Challenges in the Transition from High School \(GAO-12-594\)](#)

These resources are used to illuminate how transition-age individuals with ASD experience significant disparities relative to both their peers with disabilities and the general population across a wide range of domains, including: employment, health and safety, access to higher education, and social support. This section also calls out barriers to improving services, including: the frequency of co-occurring conditions; the complexity of clinical care, services, and supports (and the associated need for and lack of care coordination); the limited availability of specialists; and the need for additional community provider training.

Part 2. Federal Activities. The report continues by summarizing the wide range of federal and federally funded research, policies, and programs related to transition for individuals with ASD, including those at the U.S. Departments of Defense, Education, Housing and Urban Development, Justice, Transportation, and the Social Security Administration, as well as several operating divisions within the US Department of Health and Human Services – NIH, HRSA, SAMHSA, ACL, CDC and others. This exhaustive survey of initiatives includes both the small number specifically designed for adolescents and young adults with ASD and those that benefit transition-age people with ASD but are not necessarily targeted for this population. This information is consolidated in a table that can be found on pages 59-62 of the report.

The [2020 Youth Transition Plan](#) is also featured in this section. Developed by an interagency policy workgroup, Federal Partners in Transition (FPT), this document identifies several policy priorities that can support priority goals related to the transition from secondary education to postsecondary education, employment, and community living for youth with disabilities. These goals include: facilitating access to quality health care and health insurance; promoting collaboration, coordination, and cooperation among youth and adult service systems and agencies; supporting professional development for service providers; and improving education and outreach to the public regarding policy and practices governing youth transition programs.

While the majority of federal activities serve the general population or the broader cross-disability population, HRSA's Autism CARES initiatives are called out (pages 35-36, 57, and 60) for specifically targeting youth and young adults with ASD.

Part 3: Stakeholder Perspectives. This section summarizes input from public stakeholders on ASD and transition from three sources: (1) a stakeholder listening session conducted by the Office of the Assistant Secretary for Health, (2) public commentary provided to the IACC in 2016, and (3) a 2017 GAO Report of a stakeholder panel study. Feedback further confirmed the challenges, needs, and gaps identified in the demographic survey:

- The complexity and variability of ASD, particularly when there are co-occurring conditions, necessitate individualized supports.
- There is a need for comprehensive approaches to service delivery and coordination that are responsive to changing needs based on age and circumstance.
- Existing systems are overwhelmingly focused on children, with insufficient resources allocated to addressing needs related to the transition from adolescence to adulthood.
- Service needs cross a wide range of life and community domains, such as education, health/medicine, social and romantic life, mental health, communication, and transportation.
- To meet the needs of individuals along a spectrum of abilities and challenges, service systems need to be designed for a wide range of support intensity levels.
- Existing disparities in quality of and access to services and supports based on race/ethnicity, gender, socio-economic status, and location must be addressed.

Part 4: Conclusions and Recommendations. The report concludes by presenting a number of key findings and recommendations. This section highlights:

- The need for a coordinated, comprehensive approach to services and supports;
- Deficits in service coordination across systems (e.g. the gaps between Vocational Rehabilitation and Supplemental Security Income);
- Concerns for family and caregiver health and wellness, particularly for aging caregivers; and
- Gaps in data and research on transition-aged youth and young adults with ASD.

It was noted that the lack of federally funded programs and research studies focused solely on this population makes it challenging to report on outcomes and put evidence-based practices in place across settings. The report called attention to the IACC's research portfolio analyses, which have consistently indicated that less than two percent of research funding for ASD has been dedicated to addressing the needs of transition-related issues for adults. To this end, the report recommends improving epidemiological data collection and monitoring; research; and services and supports, specifically through increased training of service providers.