



May 2017

YOUTH WITH AUTISM

Federal Agencies Should Take Additional Action to Support Transition- Age Youth

Why GAO Did This Study

Research suggests that youth with ASD are less likely than youth with other disabilities to be successful in transitioning to work and postsecondary education and therefore, they may face a lifetime of reliance on public assistance. GAO was asked to examine services provided under IDEA to assist youth with ASD in transitioning to adulthood. For this report, GAO examined (1) services and supports provided to assist youth with ASD in transitioning to adulthood, (2) key challenges in successfully transitioning, and (3) the extent to which federal agencies have collaborated to assist in the transition.

GAO reviewed relevant federal laws and regulations and conducted a nationally generalizable survey of 588 school districts to gather information on services provided in school year 2015-16. GAO also interviewed federal officials and state and local stakeholders in three states selected to highlight a mix of localities with and without initiatives serving this population, urbanicity, and geographic dispersion, and GAO evaluated federal collaborative efforts against leading practices.

What GAO Recommends

GAO is making three recommendations to federal agencies, including one to Education to examine the merits and implications of amending IDEA to require earlier transition planning and one to HHS to enhance collaboration with non-IACC member agencies. Education neither agreed nor disagreed with the IDEA recommendation. The agencies generally agreed with or did not comment on other recommendations.

View [GAO-17-352](#). For more information, contact Jacqueline M. Nowicki at (617) 788-0580 or nowickij@gao.gov.

YOUTH WITH AUTISM

Federal Agencies Should Take Additional Action to Support Transition-Age Youth

What GAO Found

According to GAO's nationwide survey of school district special education directors, GAO estimates that about 85 percent of districts in school year 2015-16, provided youth with Autism Spectrum Disorder (ASD) services such as instruction on life, social, and behavioral skills, as they transition from high school to adulthood. ASD is a group of complex developmental disorders characterized by difficulties with social interactions, communication, and repetitive behaviors. Districts provided these services as part of the planning for the transition to adulthood required by the Individuals with Disabilities Education Act (IDEA). Fewer, though still a majority of, districts reported providing certain types of employment-related supports. For example, GAO estimates that 69 percent provided work experiences and 63 percent provided job coaching. While the majority of districts reported providing transition services to students with ASD, the services provided varied by factors such as the size and poverty level of the district, according to GAO's analysis of survey responses.

Youth with ASD face key challenges transitioning from high school to adulthood, such as untimely transition planning by school districts, complex adult service systems, and lack of job opportunities, according to stakeholders. IDEA requires districts to begin providing transition services when students with disabilities reach age 16, with the option to start earlier. However, according to GAO's prior work and stakeholders GAO interviewed, providing discretion in this area may not serve some students well. School officials, advocates, and others report that earlier transition planning—with age 14 commonly cited—can have multiple benefits such as allowing more time to obtain important work and academic experiences; however, the Department of Education (Education) is not funding research on the appropriate age to begin transition planning. Unless Education, which administers IDEA, examines the merits of earlier transition planning, policymakers may not have critical information when considering changes to IDEA. Currently, about 32 percent of districts begin transition planning when students are older than age 14, according to GAO's analysis of survey responses.

While the Department of Health and Human Services' (HHS) Interagency Autism Coordinating Committee (IACC) has facilitated collaboration across its member agencies, including Education, to support research for transition-age youth with ASD, it has missed opportunities to collaborate with relevant nonmember agencies. Specifically, the Autism Collaboration, Accountability, Research, Education, and Support Act of 2014 calls for the IACC to include in its strategic plan, as practicable, services for individuals with ASD. However, HHS has not regularly engaged certain federal agencies that provide services or financial assistance to transition-age youth with ASD, but are not IACC members, such as the Departments of Labor and Housing and Urban Development. These agencies are not part of working groups tasked with updating the current strategic plan nor has HHS invited them to join the IACC. As a result, IACC may continue to miss opportunities to leverage the knowledge of other agencies—a leading practice for effective federal interagency collaboration—as it works to fulfill its expanded responsibilities under the Act and improve the well-being of individuals with ASD.

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Abbreviations

ASD	Autism Spectrum Disorder
Autism CARES Act	Autism Collaboration, Accountability, Research, Education, and Support Act of 2014
CDC	Centers for Disease Control and Prevention
CMS	Centers for Medicare and Medicaid Services
DOL	U.S. Department of Labor
Education	U.S. Department of Education
EPA	Environmental Protection Agency
FPT	Federal Partners in Transition
FRPL	Free or Reduced Price Lunch
HHS	U.S. Department of Health and Human Services
HUD	U.S. Department of Housing and Urban Development
IACC	Interagency Autism Coordinating Committee
ICDR	Interagency Committee on Disability Research
IDEA	Individuals with Disabilities Education Act
IEP	Individualized Education Program
LEA	local educational agency
NLTS2	National Longitudinal Transition Study-2
OARC	Office of Autism Research Coordination
SSA	Social Security Administration
VR	Vocational Rehabilitation
WIOA	Workforce Innovation and Opportunity Act

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May 4, 2017

The Honorable Greg Walden
Chairman
Committee on Energy and Commerce
House of Representatives

The Honorable Michael C. Burgess
Chairman
Subcommittee on Health
Committee on Energy and Commerce
House of Representatives

The Honorable Christopher H. Smith
House of Representatives

The Honorable Fred Upton
House of Representatives

Students with disabilities are less likely than their peers to successfully transition to postsecondary education or the workforce, and youth with autism are even less likely to successfully transition than youth with other disabilities, according to recent research.¹ When young adults with disabilities do not successfully transition out of high school, they may face a lifetime of continued reliance on public assistance, potentially leading to substantial costs to their families, the government, and society. Commonly known as autism, Autism Spectrum Disorder (ASD) is a group of complex developmental disorders characterized by difficulties with social interactions and communication, highly focused interests, or repetitive or ritualized behaviors.²

Much of the focus on autism has been placed on early diagnosis and intervention and little is known about the services and supports provided

¹Anne M. Roux, Paul T. Shattuck, Jessica E. Rast, Julianna A. Rava, and Kristy A. Anderson, *National Autism Indicators Report: Transition into Young Adulthood* (Philadelphia, PA: Life Course Outcomes Research Program, A.J. Drexel Autism Institute, Drexel University, 2015).

²In this report, we use the following terms interchangeably: “individuals on the autism spectrum,” “individuals with autism,” “individuals/youth with ASD,” and “autistic individuals.”

to help youth with ASD begin managing their lives as adults. You asked us to study the services and supports provided to youth with ASD as they transition to adult life. This report, which builds upon our recent work identifying this population's needs,³ examines (1) the types of services and supports provided at the local level to assist youth with ASD in transitioning to adult life, (2) the key challenges for youth with ASD in successfully transitioning to adult life, and (3) the extent to which key federal agencies have collaborated to assist youth with ASD in successfully transitioning to adult life.⁴

To examine the types of services and supports provided at the local level to assist youth with ASD in transitioning to adult life and the key challenges for youth with ASD in successfully transitioning to adult life, we used multiple methodologies. We conducted a nationally representative web-based survey of 588 school districts within the 50 states and the District of Columbia to gather information on services and supports provided to students aged 16 to 21 with ASD to assist in transitioning to adult life during the 2015-16 school year, as well as challenges in providing these services. We also asked about services provided to students by level of service need. This survey had a weighted response rate of 71 percent, the results of which are generalizable. We also selected three states—Arizona, New Jersey, and South Carolina—to conduct interviews with local and state stakeholders, such as service providers and advocacy groups.⁵ We selected these states to highlight a mix of local areas with adult providers specifically involved with initiatives to serve individuals with autism and those that are not, as well as a mix of rural, suburban, and urban localities, and geographic dispersion. In two of these states (Arizona and New Jersey), we conducted site visits and phone interviews with local and state entities. As part of these local interviews, we held five discussion groups with youth with ASD and family

³GAO, *Youth with Autism: Roundtable Views of Services Needed During the Transition to Adulthood*, [GAO-17-109](#) (Washington, D.C.: Oct. 18, 2016). We convened a roundtable panel to identify the needs of transition-age youth with ASD. Because our report is intended to build on that work, we present findings from that work throughout this report.

⁴Consistent with our prior work on transition-age youth, throughout this report, we generally use the term “youth” to describe individuals aged 14 to 24, the age range when they generally may be eligible for transition services. During the transition years, youth may receive services for children, adults, or both.

⁵For this report, unless otherwise noted, we use the term “stakeholders” to include parents and family members from our discussion groups, service providers, and/or advocacy groups.

members of youth with ASD who had exited high school within the last 5 years, and we conducted interviews with officials of school districts and staff from postsecondary education institutions. We also met with public high school special education teachers and multiple adult service providers in each state. At the state level, we conducted interviews by phone with representatives of state special education, developmental disabilities, vocational rehabilitation, as well as behavioral health services agencies. We also interviewed representatives of university centers of excellence, parent training and information centers, the state developmental disabilities council, and state disability advocacy organizations. To gather additional information on service provision after high school, we conducted phone interviews in South Carolina with adult service providers and state agencies. Information gathered from our state and local interviews and discussion groups, while not generalizable, provides more in-depth examples of services provided and perspectives on the challenges facing youth with ASD in transitioning to adult life.

To examine the extent to which key federal agencies have collaborated to assist youth with ASD in successfully transitioning to adult life, we reviewed relevant federal laws, regulations, policy, and guidance and interviewed officials from the Departments of Education (Education), Health and Human Services (HHS), Housing and Urban Development (HUD), Labor (DOL), and the Social Security Administration (SSA), as well as the Interagency Autism Coordinating Committee (IACC) and the Federal Partners in Transition (FPT) interagency workgroup, which is composed of Education, HHS, DOL and SSA. We evaluated their collaborative efforts against leading federal practices for interagency collaboration, as appropriate.⁶ To inform all of our objectives, we interviewed additional stakeholders, such as employers and several national disability advocacy organizations. For more information on our scope and methodologies, please see appendix I.

We conducted this performance audit from November 2015 through April 2017 in accordance with generally accepted government auditing standards. Those standards require that we plan and perform the audit to

⁶GAO, *Results-Oriented Government: Practices That Can Help Enhance and Sustain Collaboration among Federal Agencies*, [GAO-06-15](#) (Washington, D.C.: Oct. 21, 2005) and *Managing for Results: Key Considerations for Implementing Interagency Collaborative Mechanisms*, [GAO-12-1022](#) (Washington, D.C.: Sept. 27, 2012). We reviewed collaboration efforts of the FPT against all of the leading practices for interagency collaboration. Because we have conducted recent reviews of collaboration related to the IACC, we selected the practices most relevant to the focus of our review.

obtain sufficient, appropriate evidence to provide a reasonable basis for our findings and conclusions based on our audit objectives. We believe that the evidence obtained provides a reasonable basis for our findings and conclusions based on our audit objectives.

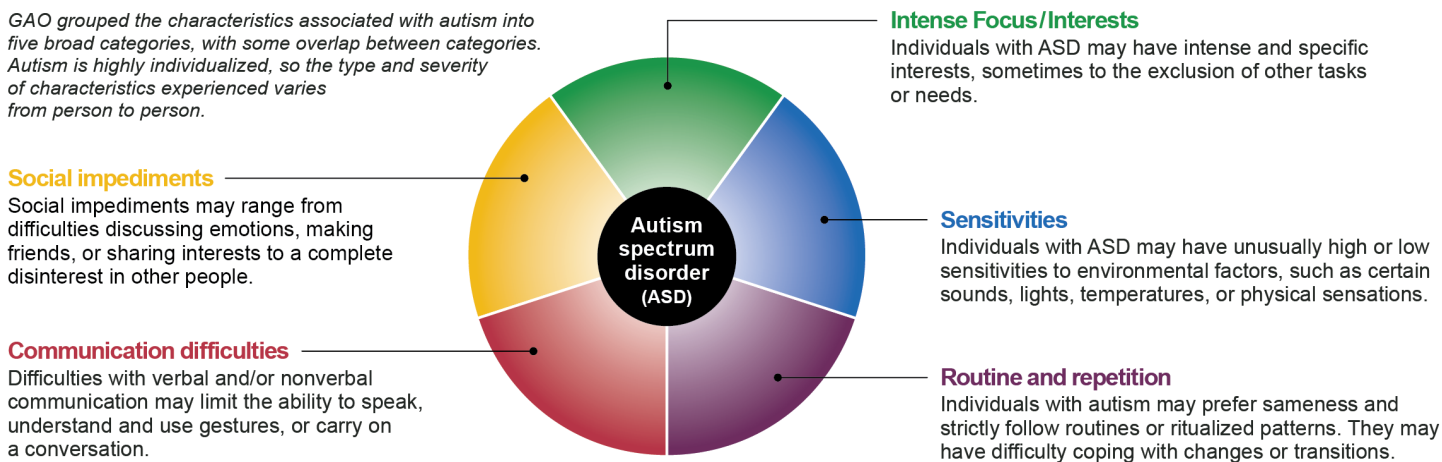
Background

Characteristics, Needs, and Outcomes of Transitioning Youth with Autism Spectrum Disorder

According to the Centers for Disease Control and Prevention (CDC), about 1 in 68 children were identified as having ASD in 2012 (about 1.5 percent of 8-year-olds).⁷ ASD is a complex developmental disorder with characteristics that can range from mild to more pronounced (see fig. 1).

Figure 1: Autism Spectrum Disorder (ASD) Characteristics

GAO grouped the characteristics associated with autism into five broad categories, with some overlap between categories. Autism is highly individualized, so the type and severity of characteristics experienced varies from person to person.



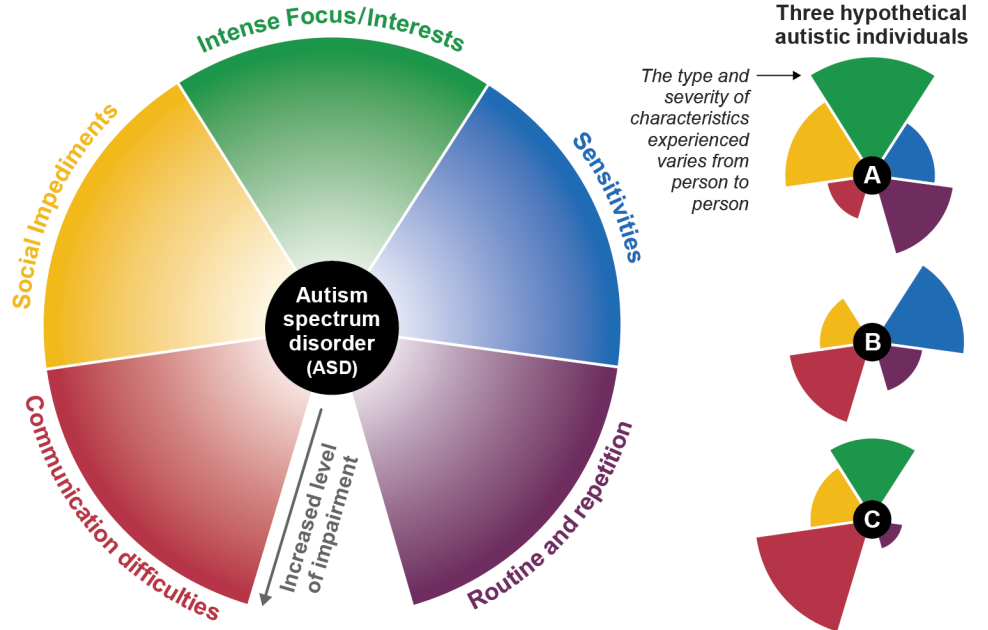
Source: GAO analysis of the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) as presented in GAO-17-109. | GAO-17-352

Each autism characteristic may vary in type and degree from person to person and can fluctuate over time. The combination of characteristics results in a highly individualized condition, as illustrated in figure 2.

⁷The Autism and Developmental Disabilities Monitoring Network is a group of programs funded by the CDC that provides estimates of the prevalence of ASD and other characteristics among 8-year-old children whose parents or guardians live in 11 sites in the United States.

Figure 2: Variation in Autism Spectrum Disorder Characteristics

GAO grouped the characteristics associated with autism into five broad categories, with some overlap among categories.



Source: GAO analysis of the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) as presented in GAO-17-109. | GAO-17-352

To successfully transition into adulthood, youth with ASD need to be able to access services that are individualized, timely, equitable, and community- and evidence-based, among other things, according to a roundtable panel we convened in 2016 to examine the needs of transitioning youth with ASD.⁸ The panel also identified 14 key services and supports that may help youth with ASD attain the goals of education, employment, health and safety, independent living, and community integration as they transition to adulthood (see table 1).

⁸ GAO-17-109.

Table 1: Key Services Needed to Support Transitioning Youth with Autism Spectrum Disorder

Behavioral interventions	Mental health care
Case management/ coordination	Postsecondary education planning and supports
Communication services	Residential supports
Day programming	Social supports
Family education and supports	Transition planning services
Life skills education and experience	Transportation supports
Medical care	Vocational supports

Source: GAO-17-109 | GAO-17-352

Recent research analyzing the outcomes of youth with ASD suggests that they encounter obstacles to attaining their goals for adulthood. According to analysis of data from Education’s National Longitudinal Transition Study-2 (NLTS2), in 2009:

- 36 percent of young adults with ASD had attended some type of postsecondary education institution.⁹ Of those youth, 32 percent had attended a 4-year college; 70 percent had attended a 2-year college; and 33 percent had attended a vocational, business, or technical school.¹⁰
- 19 percent of autistic adults in their early 20s had lived independently at some point, either with or without supports. Fourteen percent had lived in a supervised setting, such as a group home or medical facility, which may have provided services such as life skills education or vocational supports. The analysis further indicates that young adults with autism are less likely to live independently than youth with other

⁹Roux et al. NLTS2 was funded by Education and documented the experiences of a national sample of students as they moved from secondary school into adult roles. The students were 13 to 16 years old in 2000 and 21 to 25 years old in 2009 at the final data collection.

¹⁰These percentages sum to greater than 100 percent because some students may have attended more than one type of postsecondary institution. These data were reported by Roux et al. Education also produced a peer-reviewed report using the same data, which found that 44 percent of youth with autism had attended a postsecondary school. See 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, *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*, NCSER 2011-3005 (SRI International, Menlo Park, CA: September 2001).

disabilities, including intellectual disabilities and emotional disturbances.¹¹

- About one-third of young adults with autism did not participate in any community activities, and one-quarter had not had any contact with friends for at least a year.¹²

School-Based Special Education under IDEA

In elementary and secondary school, students with disabilities—including students with autism—are entitled to receive special education and related services through the Individuals with Disabilities Education Act (IDEA), which is overseen at the federal level by Education.¹³ Part B of IDEA requires states to make a free appropriate public education in the least restrictive environment available to eligible children with disabilities as a condition of grant eligibility.¹⁴ In general, under Part B, Education provides formula grants to assist states and school districts to pay the excess costs of providing special education and related services to eligible students with disabilities, including those with autism, beginning at age 3 and lasting through 21, depending on state law or practice.¹⁵ In general, school districts provide public school students with special education and related services—such as speech therapy, psychological services, and physical therapy—tailored to their needs based on an individualized education program (IEP).¹⁶ An IEP is a written statement developed by a team of school officials, parents, the student if appropriate, and at the discretion of the parent or school, other individuals who have knowledge or special expertise regarding the student. The IEP

¹¹The study found that 34 percent of youth with an intellectual disability and 66 percent of youth with an emotional disturbance had lived independently. See Roux et al.

¹²Roux et al.

¹³See Individuals with Disabilities Education Improvement Act of 2004, Pub. L. No. 108-446, 118 Stat. 2647 (codified as amended at 20 U.S.C. §§ 1400-1482).

¹⁴The least restrictive environment requirement means that to the maximum extent appropriate, students with disabilities are to be educated with other children who are not disabled. 20 U.S.C. § 1412(a)(5)(A). Least restrictive environment is determined individually for each child served under IDEA.

¹⁵In order for a child to be eligible to receive services under IDEA, a child must have a disability, such as autism, as defined in the Act. 20 U.S.C. § 1401(3).

¹⁶Federal law generally requires school districts to also provide special education and related services to children they place in or refer to private schools. However, children whose parents choose to place them in private school without a school district placement or referral generally have no individual entitlement to receive some or all of the services they would receive if enrolled in a public school.

includes, among other information, a statement of the child's present levels of academic achievement and functional performance, annual goals and a statement of the special education and related services and supplementary aid and services needed to attain those goals. Beginning no later than the first IEP to be in effect when the student turns age 16, or younger if determined appropriate by the IEP team, a student's IEP must include postsecondary goals and the transition services needed to assist the student in reaching those goals.¹⁷ To the extent appropriate, and with the consent of the parents or student who has reached the age of majority under state law, schools must invite representatives from state vocational rehabilitation (VR) agencies to IEP team meetings where postsecondary goals and transition services will be discussed. These students remain eligible for transition planning and services, as well as other IDEA services, until they exit high school.¹⁸

Title I of the Rehabilitation Act of 1973 (Rehabilitation Act), as amended, contains new federal requirements in the state VR program, administered by Education, that require state VR agencies to provide pre-employment transition services to students with disabilities who are eligible or potentially eligible for VR services.¹⁹ State agencies may also provide

¹⁷Transition services include instruction, related services, community experiences, the development of employment and other post-school adult living objectives, and when appropriate, acquisition of daily living skills and functional vocational evaluation. 20 U.S.C. § 1401(34). IDEA and its implementing regulations require that beginning no later than the first IEP in effect when the student turns 16, or younger if determined appropriate by the IEP team, school districts must ensure that the student's IEP includes appropriate measureable postsecondary goals based on age-appropriate transition assessments related to training, education, employment, and where appropriate, independent living skills; and transition services needed to assist the student in meeting those goals. 20 U.S.C. § 1414(d)(1)(A)(i)(VIII) and 34 C.F.R. § 300.320(b). According to IDEA and its implementing regulations, Education is to review states' compliance with the IDEA transition services requirement through states' annual performance reports. If a state does not report 100 percent compliance (percent of students with transition plans age 16 and above) with the secondary transition services requirement, it must provide detailed information on correction of the non-compliance. For the purpose of this report, we refer to the inclusion of transition services in a student's IEP as "transition planning."

¹⁸Students remain eligible for transition planning and services, as well as other IDEA services, until they graduate from high school with a regular high school diploma or exceed the earlier of age 21 or the eligibility age for a free appropriate public education under state law. While federal law authorizes students to receive a free appropriate public education up until age 22, eligibility for students aged 18 and older is determined by states. 20 U.S.C. § 1412(a)(1) and 34 C.F.R. § 300.102(a).

¹⁹ See Workforce Innovation and Opportunity Act, Pub. L. No. 113-128, § 422, 128 Stat. 1425, 1657-59 (2014) (codified at 29 U.S.C. § 733).

transition services to groups of students and youth with disabilities prior to or after applying for VR services. Finally, VR agencies may provide individualized VR services including individualized transition services, to students and youth with disabilities who have been determined eligible for VR services under an approved individualized plan for employment under the VR program.²⁰ Students may apply for and be determined eligible for VR services prior to graduating from high school, and youth may apply for and be determined eligible for VR series prior to reaching adulthood.

System for Adult Services

Generally, as they enter adulthood, youth and young adults with ASD may seek to obtain needed services from the state adult service systems, which are funded by multiple federal agencies:

- HHS's Centers for Medicare & Medicaid Services (CMS) oversees Medicaid, which can be used to fund long-term and home- and community-based services.²¹ These services are generally administered to eligible individuals with ASD through state agencies serving individuals with developmental disabilities or disabilities more broadly.
- Education's Rehabilitation Services Administration, within the Office of Special Education and Rehabilitative Services, funds the VR State Grants program to assist individuals with disabilities including transition-age students and youth with ASD in developing the skills to prepare for, secure, retain, advance in, and regain employment. This program is in the form of federal/state matching grants provided to state VR agencies.²²

²⁰29 U.S.C. § 723.

²¹Medicaid is a joint federal-state financing program for health care for certain low-income and medically needy individuals. States design and administer their Medicaid programs within broad federal rules and according to a state plan approved by CMS. States are required to cover all medically necessary state plan services, including institutional and community-based services, for beneficiaries under age 21; however, the majority of home- and community-based services provided through Medicaid are covered by optional state waivers. Services provided with these waivers are individualized and may include case management, personal care attendants, or day habilitation.

²²To be eligible for VR services, an individual must (1) be an "individual with a disability," meaning a person who has a physical or mental impairment which constitutes or results in a substantial impediment to employment for the individual, and who can benefit from VR services to achieve an employment outcome; and (2) require VR services to prepare for, secure, retain, advance in, or regain employment. State VR agencies determine individual's eligibility for VR services.

Interagency Autism Coordinating Committee

- SSA provides cash benefits to qualifying individuals through the agency's Supplemental Security Income (SSI) and Disability Insurance (DI) programs.²³ Individuals can apply for benefits through SSA field offices.
- DOL provides funding for employment and training for a broad array of individuals with barriers to employment, including youth and those with disabilities, often through the One-Stop delivery system.²⁴ HUD provides funds for rental assistance for low-income individuals with disabilities through various programs, offers online tools to assist with locating housing resources, and funds Housing Counseling Agencies that assist families and individuals seeking affordable housing.²⁵

The Autism Collaboration, Accountability, Research, Education, and Support Act of 2014 (Autism CARES Act) reauthorized the Interagency Autism Coordinating Committee,²⁶ which is led by HHS and composed of representatives from multiple HHS subagencies, Education, the Department of Defense (DOD), and the Environmental Protection Agency

²³The SSI program provides financial assistance to eligible individuals who are age 65 or older, blind, or disabled, and who have limited income and resources. 42 U.S.C. § 1381a. Children under age 18 may qualify for SSI benefits if they meet SSA's disability definition and financial eligibility requirements. 20 C.F.R. § 416.906. Individuals known as "disabled adult children" can receive DI benefits if they are age 18 or older, were disabled before age 22, and have at least one parent who also receives Social Security payments because of retirement or disability, or who is deceased but worked long enough to be eligible to receive benefits. 20 C.F.R. § 404.350(a).

²⁴Under the Workforce Innovation and Opportunity Act (WIOA), each state must establish a One-Stop delivery system to provide career services and access to training. Under Title I, three state formula grant programs for youth, adults, and dislocated workers authorize funding for employment and training activities available through the system of One-Stop centers (also known as American Job Centers) and provided by service providers in local communities.

²⁵For example, HUD administers the Section 811 Supportive Housing for Persons with Disabilities program, which funds supportive housing for very low-income persons with disabilities, and the Housing Choice Voucher program, which can be used by very low-income persons with disabilities to find affordable, private housing of their choice.

²⁶Autism CARES Act of 2014, Pub. L. No. 113-157, 128 Stat. 1831. The IACC was originally established under the Children's Health Act of 2000 and reauthorized under the Combating Autism Act of 2006 (CAA). Children's Health Act of 2000, Pub. L. No. 106-310, § 104, 114 Stat. 1101, 1109 and Combating Autism Act of 2006 Pub. L. No. 109-416, § 3, 120 Stat. 2821, 2827-28.

(EPA), as well as certain non-federal stakeholders.²⁷ Among other things, the IACC is responsible for developing and annually updating a strategic plan with budgetary recommendations for ASD research. The 2013 strategic plan (the most recent plan), is divided into seven general topic areas that were created to address critical gaps and opportunities. Each general topic area includes specific objectives and a recommended budget for associated research-related activities. The 2014 reauthorization expanded the scope of the strategic plan to include, as practicable, services and supports.²⁸ The strategic plan is intended to promote public-private coordination and community engagement and to accelerate research and service efforts to improve the health and well-being of individuals with ASD. The IACC is also responsible for monitoring ASD research across federal agencies, and the 2014 reauthorization also expanded this monitoring role to include, as practicable, monitoring of services and support activities. In the past, the IACC has fulfilled the responsibility for monitoring research by tracking and compiling information on ongoing research in the field. The Autism CARES Act led to the creation of the role of the Autism Coordinator within HHS, separately but in coordination with the IACC, to oversee and implement federal ASD activities nationwide, taking into account the strategic plan developed by the IACC, and ensure that federal ASD activities are not unnecessarily duplicative.²⁹

We have conducted previous work on IACC's federal autism activities. In 2013 we reported that the IACC's and federal agencies' efforts to coordinate and monitor federal autism activities were limited.³⁰ Specifically, IACC members provided mixed views on the usefulness of the IACC's meetings, strategic plan, and portfolio analysis in aiding

²⁷In accordance to the requirements of the Autism CARES Act, federal members include representatives of Education and DOD, as well as from the Administration for Children and Families, Administration for Community Living, Agency for Healthcare Research and Quality, CDC, CMS, Food and Drug Administration, Health Resources and Services Administration, and five institutes within and the director of the National Institutes of Health. The EPA is not a statutorily required member. The reauthorized IACC also includes representatives from advocacy groups, university professors, individuals with autism, and parents of children with autism.

²⁸See Autism CARES Act of 2014, § 5.

²⁹See Autism CARES Act of 2014, § 2.

³⁰GAO, *Federal Autism Activities: Better Data and More Coordination Needed to Help Avoid the Potential for Unnecessary Duplication*, [GAO-14-16](#) (Washington, D.C.: Nov. 20, 2013).

coordination and monitoring activities, and only some agencies regularly used the committee's strategic plan and research funding analysis.³¹ Additionally, we found that shortcomings in the data the IACC used for its research funding analysis limited its ability to coordinate HHS autism activities and monitor federal autism activities. We found that, collectively, these weaknesses limited the IACC's ability to monitor its progress. For a complete list of our previous work in this area, see the Related GAO Products page at the end of this report.

³¹The IACC holds meetings and issues reports as a means to coordinate HHS autism efforts and monitor federal autism activities.

Most School Districts Reported Providing Life and Social Skills Services; Other Services Varied Based on Factors Such as Size and Poverty Level

School Districts Reported Providing Life and Social Skills Services; Fewer Provided Services to Prepare for Employment, Housing, and Transportation

Based on the results of our nationally generalizable school district survey, we estimate that in school year 2015-16 most school districts (about 85 percent) provided transition-age students with ASD instruction on life and social skills, as well as behavioral skills (see fig. 3),³² services we previously reported such youth may need to support their transition to adulthood.³³ Self-advocacy (87 percent), social (86 percent), and organizational (86 percent) skills were provided by the most districts, according to our survey. Schools may employ different strategies for providing these services based on individual student needs. For instance, officials we interviewed in one district said that for many students with occasional behavior issues, staff teach students how to cope with and have control over their emotions. However, if a student needs intensive behavioral supports, the district may send the student to a nonpublic school that specializes in serving youth with ASD. The officials noted that

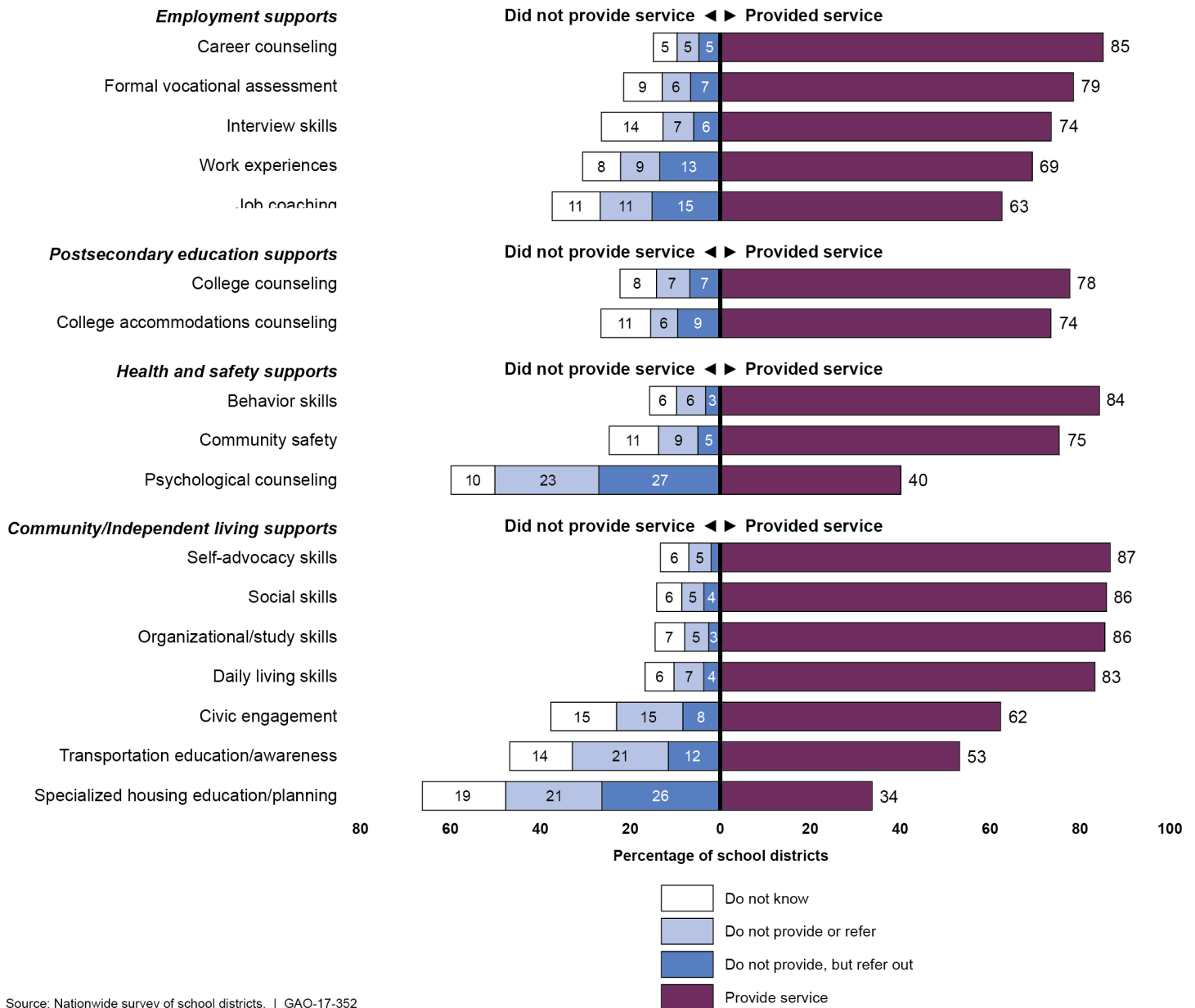
³²In our survey, we asked school districts which services and supports to assist in transitioning to adult life they provided to students aged 16-21 with ASD in special education during the 2015-16 school year. Transition services provided through special education are determined by an IEP team and vary based on the needs of each individual student. Therefore, these estimates do not reflect services each transition-age student received, but rather services the district provided to transition-age students with ASD in aggregate. Further, in our survey we did not ask about all services districts may provide as part of special education. We only asked about services specifically aimed at assisting youth in transitioning beyond high school. All estimates presented in this report from this survey have a margin of error of plus or minus 11.8 percentage points or fewer at the 95 percent confidence level, unless otherwise noted.

³³In [GAO-17-109](#), we reported on 14 key services and supports that may help youth with ASD in attaining goals of adulthood (also listed in table 1 of this report). Throughout this report, we provide examples from our interviews of how these 14 services are provided.

it is difficult to find teachers who understand how to support students with intense behavior issues.³⁴

³⁴Behavioral interventions may include, for example, identifying the reason for challenging behavior and teaching a positive behavior as a replacement, step-by-step teaching and practicing of skills, or teaching awareness of thoughts and feelings to manage responses to them. For example, one specific intervention, Applied Behavior Analysis, uses a structured system of rewards to reinforce the desired behavior and has been the subject of extensive research. Our survey did not ask about the specific types of behavior interventions used by the districts.

Figure 3: Estimated Percentage of School Districts That Reported Providing Transition Services to Youth with Autism Ages 16-21, School Year 2015-16



Source: Nationwide survey of school districts. | GAO-17-352

Notes: All estimates in this figure have a margin of error of plus or minus 7.2 percentage points or fewer, at the 95 percent confidence level. For this question in our survey, we asked school districts about services and supports they provide to students aged 16-21 with Autism Spectrum Disorder (ASD) in special education to assist in transitioning to adult life. We gave respondents four response options: yes, provide service; no, do not provide but refer out; no, do not provide, do not refer out; and do not know. "Refer out" indicates that school staff do not provide or pay for the service but refer the

**Life Skills Education and Experiences:
Examples of Key Service Needed to
Support Transitioning Youth with
Autism**

Self-advocacy skills: Officials we interviewed at one school district reported that case managers work with students to build the skills they need to communicate their wants, needs, and to advocate for themselves.

Daily living skills: Teachers in one high school serving students with moderate- and high-intensity needs told us students take a weekly assisted daily living class that includes learning housekeeping, hygiene, washing dishes, and basic cooking recipes.

Source: GAO interviews. | GAO-17-352

**Social Supports: Examples of Key
Service Needed to Support Transitioning
Youth with Autism**

Social skills: In one high school, staff reported using community-based experiences to help students practice social skills, such as visiting the local food court to order food, pay, eat with friends, and learn how to wait for others to finish eating before leaving the table. In another high school, teachers reported using role-playing to help students with Autism Spectrum Disorder practice their social skills.

Source: GAO interviews. | GAO-17-352

student to a service provider (likely in the community). We do not have information on the formality of the referral or whether the student's family pursued and received such services from an outside provider. Transition services provided through special education are determined by an individualized education program team and vary based on the needs of each individual student. Therefore, these estimates do not reflect services each transition-age student received, but rather services the district provided to transition-age students with ASD in aggregate.

Fewer, though still a majority of, school districts reported providing certain types of services to support the transition to employment, according to our survey. Specifically, while an estimated 85 percent of districts reported providing career counseling, we estimate that 74 percent provided interview skills, 69 percent provided work experiences, and 63 percent provided job coaching. In Arizona and South Carolina, state VR officials reported partnering with some school districts to provide employment-related services. For example, in South Carolina, VR state officials told us they partner with some school districts to provide job coaches to high school students with disabilities, including ASD.³⁵ In all three states in our review, state VR agency officials told us they were developing plans for how they will enhance pre-employment transition services to school-age students with disabilities.³⁶

Certain mental health and independent living skills were provided by the fewest districts, according to our survey. Specifically, an estimated 40 percent reported providing one-on-one or group psychological counseling. About one-half of districts reported providing education and planning on transportation options and 35 percent of school districts reported providing housing education and awareness. As figure 3 illustrates, more districts reported referring students out to community providers for psychological counseling and housing education compared to other

³⁵This effort was a Project SEARCH program, according to South Carolina VR officials. Project SEARCH partners with employers to provide work experience programs to students in their last year of high school. In addition to an internship, students take classes at the work site in life and work readiness skills.

³⁶The Rehabilitation Act, as amended by WIOA, places additional emphasis on the provision of services to students and youth with disabilities to ensure that they have meaningful opportunities to receive the training and other services they need to achieve competitive integrated employment. For example, states must reserve no less than 15 percent of the funds they received under the Vocational Rehabilitation State Grants program to provide pre-employment transition services to students with disabilities in need of such services who are eligible or potentially eligible for VR services. Pub. L. No. 113-128, § 419, 128 Stat. 1425, 1656 (2014) (codified at 29 U.S.C. § 730(d)). Such pre-employment transition services may include job exploration, counseling, self-advocacy instruction, work-based learning experiences, and workplace readiness training. 29 U.S.C. § 733(a)-(b).

Vocational Supports: Examples of Key Service Needed to Support Transitioning Youth with Autism

Work experience: In one high school we visited, students begin with in-house jobs, such as custodial work, shredding, maintaining the fish pond, and gardening at the school. Once students demonstrate they are capable of these work experiences, they move on to work experiences in the community. According to special education teachers, at the job sites paraprofessionals make sure no one is taking advantage of the students and also supervise the student to make sure they are doing the work sufficiently.

Job coaching: Administrators from one school district told us job coaches help students stay focused on the job, and having a sufficient number of job coaches is important to being able to supervise the students.

Source: GAO interviews. | GAO-17-352

services; the extent to which these students actually receive these services is unknown. One reason school districts do not typically provide housing education and planning is that it may not be a priority for families as youth are leaving school. As one school district official said, parents typically are not looking for housing options for their transition-age youth.

Stakeholders we interviewed emphasized that the services provided to each individual student with ASD vary widely based on individual need and goals for transition. Likewise, in our survey school districts reported differences in the services provided to transition-age students with low-, moderate-, and high-intensity needs.³⁷ This may be expected given that IDEA requires school districts to determine special education services based on the individual needs of each student; moreover, the needs of individuals on the spectrum vary widely.³⁸ For example, we estimate that in the 2015-16 school year, a higher percentage of districts provided students with low-intensity needs with college counseling compared to those with moderate- and high-intensity needs. In contrast, a higher percentage of districts provided students with moderate- and high-intensity needs with daily living skills compared to those with low-intensity needs in that same year. In general, for the majority of transition services we asked about, a higher percentage of districts reported providing services to students with high- and moderate-intensity needs. (See table 2 for the services most and least frequently provided by level of student need).

³⁷In addition to asking about services provided to any students aged 16-21 with ASD in special education (as shown in fig. 3), our survey also asked about the services provided by the student level of need. Specifically, we asked how often school districts provided each service to students aged 16-21 with ASD with low-, moderate-, and high-intensity service needs during the 2015-16 school year.

³⁸In the survey, we used the following definitions of low-, moderate-, and high-intensity service needs, based on the U.S. Department of Education's environmental categories for IDEA reporting: We defined students with low-intensity service needs as those students who spend 80 percent or more of their day in the regular classroom; students with moderate-intensity service needs as those students who spend between 79 and 40 percent of their day in the regular classroom; and students with high-intensity service needs as those students who spend less than 40 percent of their day in the regular classroom. These terms are not found in IDEA or the Rehabilitation Act.

Table 2: Transition Services School Districts Reported Providing to Youth with Autism Ages 16-21 of Varying Needs, School Year 2015-16

by Estimated Percent

Student need	Three services districts most commonly reported they frequently provided	Three services districts most commonly reported they never or rarely provided
Low intensity	<ul style="list-style-type: none"> Organizational/study (59) Self-advocacy (58) Career counseling (54) 	<ul style="list-style-type: none"> Specialized housing education (50) Psychological counseling (45) Transportation education (42)
Moderate intensity	<ul style="list-style-type: none"> Social (71) Behavior (70) Daily living (69) 	<ul style="list-style-type: none"> Specialized housing education (38) Psychological counseling (38) Transportation education (32)
High intensity	<ul style="list-style-type: none"> Daily living (90) Behavior (86) Social (81) 	<ul style="list-style-type: none"> College accommodations counseling (56) College counseling (53) Psychological counseling (40)

Source: GAO survey of school districts. | GAO-17-352

Note: All estimates in this table have a margin of error of plus or minus 10.1 percentage points or fewer, at the 95 percent confidence level. Transition services provided through special education are determined by an individualized education program team and vary based on the needs of each individual student. Therefore, these estimates do not reflect services each transition-age student received, but rather services the district provided to transition-age students with Autism Spectrum Disorder in aggregate.

District-Provided Transition Services Varied by District Size and Poverty Level

While the majority of school districts reported providing some types of transition services to students with ASD, the specific services that districts reported providing varied depending on the size and poverty level of the district, according to our analysis of school districts' survey responses. In particular, we estimate that a higher percentage of large school districts generally reported providing transition services compared to small school districts, and a higher percentage of low-poverty school districts reported providing transition services compared to high-poverty school districts for certain services.

District Size

According to our analysis of survey responses, a higher percentage of large school districts generally reported providing transition services compared to small school districts.³⁹ When comparing larger school districts (those serving more than the median number of students per district) to smaller districts (those serving fewer than the median number

³⁹Transition services provided through special education are determined by an IEP team and vary based on the needs of each individual student. School districts reporting that they did not provide certain services may not have had students in need of such services. We did not assess school districts' compliance with IDEA as part of this study.

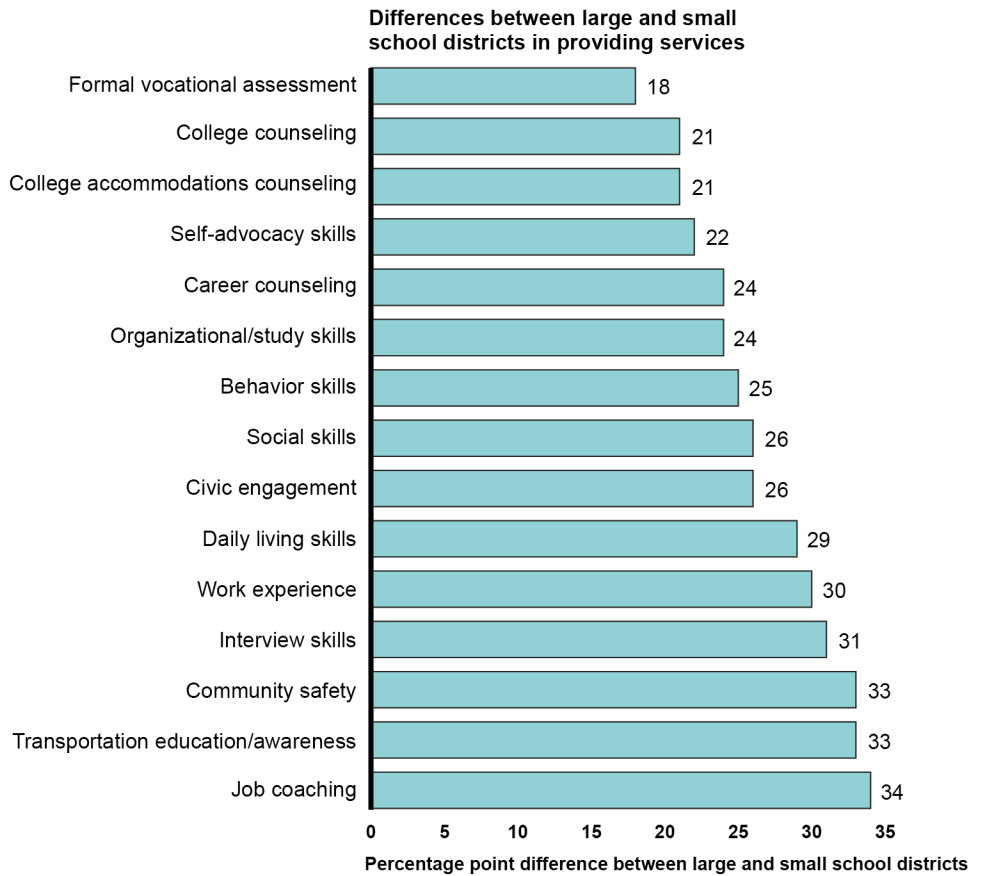
of students per district),⁴⁰ we estimate a difference of roughly 30 percentage points in providing several services to support the transition to employment, daily living skills, training on community safety, and education on and awareness of transportation options (see fig. 4).⁴¹ For example, we estimate 82 percent of larger districts provided work experience compared to 52 percent of smaller districts. Similarly, we estimate 87 percent of larger districts provided interview skills training compared to 56 percent of smaller districts. The differences may be because larger districts are better able to provide services in-house, as—for many of these services—a higher percentage of small school districts reported referring students to other providers.⁴² In addition, a higher percentage of respondents for smaller districts reported that they did not know if the school districts provided the services, compared to larger school districts.

⁴⁰The median of the population we defined was 1,110 total students (inclusive of all grades) in the district. For the purpose of this analysis, we defined smaller districts as those with total student size below the median number of students and larger districts as those with total student size above the median.

⁴¹To support the estimated differences identified in figure 4, we conducted a multivariate analysis for each of the 17 services we asked about in our survey. Based on these analyses, the estimated differences by size generally remain statistically significant when controlling for several other school district characteristics, such as poverty status, urbanicity, racial composition, and charter status. See appendix I for more details.

⁴²It is possible these differences are in part because larger districts are likely to have larger numbers of students with ASD; therefore, larger districts may need to provide a wider array of services to address the needs of more students.

Figure 4: A Higher Percentage of Large School Districts Provided Transition Services to Youth with Autism Ages 16-21 in Special Education Compared to Small Districts, School Year 2015-16



Source: GAO survey of school districts. | GAO-17-352

Note: All estimates in this figure have a margin of error of plus or minus 13.8 percentage points or fewer, at the 95 percent confidence level. For the 15 services shown in this graphic, all estimates are generally statistically significant when controlling for other school district characteristics such as poverty status, urbanicity, racial composition, and charter status. For the purpose of this analysis, we defined smaller districts as those with total student size below the median number of students and larger districts as those with total student size above the median. Transition services provided through special education are determined by an individualized education program team and vary based on the needs of each individual student. Therefore, these estimates do not reflect services each transition-age student received, but rather services the district provided to transition-age students with Autism Spectrum Disorder in aggregate.

Services provided in school also varied by the type of community where the school district was located—urban, suburban, or rural—according to our analysis of school districts’ survey responses, but in some cases this was related to district size. We estimate that smaller urban and suburban districts were significantly more likely to provide certain vocational

supports (job coaching, interview skills, and formal vocational assessment), as well as daily living skills, transportation education and awareness, community safety, civic engagement, and behavior skills when compared to smaller rural districts. However, when we compared larger urban and suburban districts to larger rural districts, the differences in services were not statistically significant.

Poverty

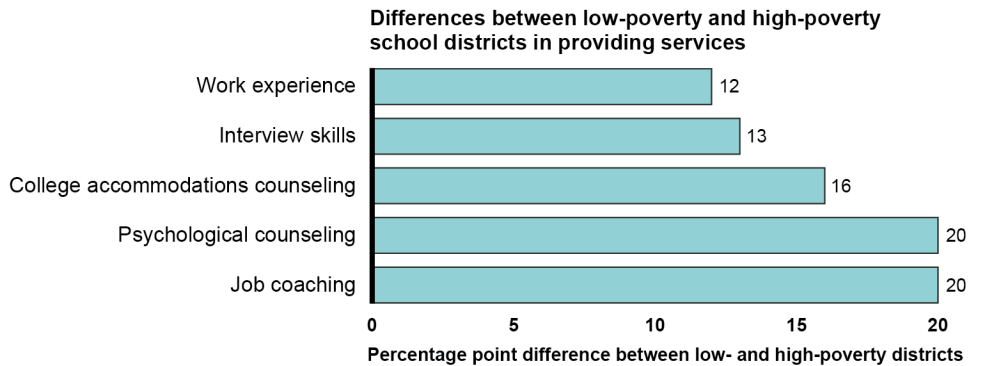
Based on our survey, we estimate that a higher percentage of low-poverty school districts reported providing transition services compared to high-poverty school districts for certain services.⁴³ For example, we estimate that 70 percent of low-poverty districts provided job coaching to transition-age youth with ASD compared to about 50 percent of high-poverty districts. Similarly, we estimate that 58 percent of low-poverty school districts provided one-on-one or group psychological counseling to transition-age youth with ASD compared to roughly 38 percent of high-poverty districts—a difference of about 20 percentage points (see fig.5).⁴⁴ In one high-poverty school district we visited, teachers and administrators said they had limited funding to enable students to get experiences outside of the school. Specifically, they said transportation and supervision costs make it difficult to provide students with community experiences. In our 2016 report on the needs of youth with ASD, the roundtable panel emphasized the importance of providing some educational services outside the classroom and locating services in the neighborhoods where youth live. Our panelists noted that many life skills, such as grocery shopping or taking a bus, are best learned experientially—by practicing them in the community—especially for youth with ASD who may have difficulty transferring skills learned in one location, such as the classroom, to another environment, such as the community.⁴⁵

⁴³Transition services provided through special education are determined by an IEP team and vary based on the needs of each individual student. School districts reporting that they did not provide certain services may not have had students in need of such services. We did not assess school districts' compliance with IDEA as part of this study.

⁴⁴To support the estimated differences identified in figure 5, we conducted a multivariate analysis for each of the 17 services we asked about in our survey. Based on these analyses, the estimated differences by poverty level generally remained statistically significant for 5 of the 17 services when controlling for several other school district characteristics such as size, urbanicity, racial composition, and charter status. See appendix I for more details.

⁴⁵[GAO-17-109](#).

Figure 5: A Higher Percentage of Low-Poverty School Districts Provided Certain Transition Services to Youth with Autism Ages 16-21 in Special Education Compared to High-Poverty Districts, School Year 2015-16



Source: GAO survey of school districts. | GAO-17-352

Note: All estimates in this figure have a margin of error of plus or minus 14.8 percentage points or fewer, at the 95 percent confidence level. For the five services shown in this graphic, all estimates are generally statistically significant when controlling for other school district characteristics such as size, urbanicity, racial composition, and charter status. For the purpose of this analysis, low-poverty districts were defined as those in which 25 percent or fewer students were eligible for free or reduced price lunch, and high-poverty districts were those in which more than 75 percent of students were eligible. See appendix I for more details. Transition services provided through special education are determined by an individualized education program team and vary based on the needs of each individual student. Therefore, these estimates do not reflect services each transition-age student received, but rather services the district provided to transition-age students with Autism Spectrum Disorder in aggregate.

Adult Service Providers Offer Employment and Other Transition Services to Young Adults after Leaving High School, as Seen in Selected States
 Vocational Supports and Day Programming

Adult service providers offered various types of services to transition-age young adults with ASD as they transition from high school to adulthood.

Across the three states in our review, most state officials and providers of developmental disabilities and VR services reported offering vocational supports and some offered day programming to young adult clients with ASD—services we previously reported such youth may need to support

Day Programming: Examples of Key Service Needed to Support Transitioning Youth with Autism

A day program in Newark, New Jersey serves adults with Autism Spectrum Disorder with high intensity needs from low-income families in the Newark community. The day program focuses on providing adult daily living skills, community exploration, pre-vocational skills, and social and emotional skills. Clients are served in small group environments. The staff said that while the program has a large waiting list it is important to keep the ratio of clients to staff small to ensure overall quality.

Source: GAO interviews. | GAO 17 352

their transition to adulthood.⁴⁶ For example, in Arizona one developmental disabilities service provider offered its adult clients supervised employment in group settings both at businesses in the community and in-house at an adult center. Another service provider ran a vocational training program for young adults with ASD. The program has a number of work areas, such as reception, technology, and design, in which the client chooses one area to train in for a year. In addition to learning the skills for a specific work area, youth learn pre-employment skills such as getting along with others, following instructions, and appropriate work etiquette. A few providers we interviewed sent their clients to workplaces with a coach to supervise and assist them on the job, with the level of coaching determined by the needs of the individual. For example, one provider said they have staff check on some clients at their place of work for an hour three times a week, while other clients who have a higher level of need have a full-time coach.

Residential Supports

Residential Supports: Examples of Key Service Needed to Support Transitioning Youth with Autism

One service provider in Princeton, New Jersey provides residential group housing to the majority of the adults in its day program. The group homes and apartments have 24-hour supervision.

A service provider in Phoenix, Arizona offers a new 2-year program designed for young adults age 18 and older. Clients live in apartments and work on independent living skills and community integration. They look for part-time paid employment in a competitive field of their choice. The provider offers 36 courses developed to teach the skills needed to live independently such as personal safety, personal finance, and advocacy. For example, as they are learning about personal finance, they create budgets and go to the bank to make deposits.

Source: GAO interviews. | GAO-17-352

Some of the adult service providers we interviewed reported providing residential supports—another service we previously identified that youth may need to support their transition to adulthood—funded either through the state developmental disabilities services agency or private, out-of-pocket payments.⁴⁷ In Arizona and South Carolina, a few adult service providers we interviewed were developing housing or independent living programs for individuals with ASD. For example, a provider in Arizona recently started a residential independent living program for individuals in its vocational program. The program serves six individuals and has a small waiting list. Individuals initially receive training on using public transportation, managing their own finances, and safety skills for being in the community and at home. They then move to supervised apartments with the ultimate goal of eventually living in apartments independently. In South Carolina, a non-profit organization serving adults with ASD was in the process of establishing a new independent living program with the goal of helping individuals live independently in an environment that meets their needs and interests.

⁴⁶GAO-17-109.

⁴⁷GAO-17-109.

Postsecondary Education

Postsecondary Education Planning and Supports: Examples of Key Service Needed to Support Transitioning Youth with Autism

In South Carolina, one non-profit started a college mentor program to assist college students with ASD in navigating the organizational side of their postsecondary education at a local technical college. The mentors help the individual learn the way around campus and how to handle challenging social situations. The mentors also assist the participants with homework assignments, developing social networks, and they help with communicating between the student and the college counselors, professors, and parents.

In New Jersey, a community college runs a program for young adults with intellectual disabilities. The program provides students with career exploration and experiences, academic experiences, independent living skills, and social experiences. Each student is paired with a peer mentor who provides academic, social, and emotional supports.

Source: GAO interviews. | GAO-17-352

Postsecondary education supports is another service area we previously identified that youth with ASD may need to support their transition to adulthood,⁴⁸ and representatives of postsecondary education institutions we interviewed in three states reported providing their students with ASD with accommodations, as they reported they do for all students with disabilities who self-identify and show need for an accommodation. Services commonly provided, according to college officials, include instruction in time management and organizational skills, or accommodations such as assistive technology or additional time and a distraction-free location for test-taking. A few of the colleges we contacted also had specialized postsecondary education programs for individuals with developmental and intellectual disabilities that focused on helping them prepare for employment and independent living. However, such programs may be cost prohibitive for many families, and some students may only participate for 1 or 2 years due to the cost, according to one college administrator.

⁴⁸[GAO-17-109](#).

Family Education and Other Supports

Family Education and Supports: Examples of Key Service Needed to Support Transitioning Youth with Autism

In Princeton, New Jersey, staff at one service provider visit their adult clients and their families at home to help establish independent living routines. For example, staff will help set up systems to assist clients in becoming more independent in caring for themselves or doing chores around the house.

At a service provider in South Carolina, staff develop behavior plans and provide parents of adult clients with training on addressing behavior issues.

Source: GAO interviews. | GAO-17-352

Non-profit advocacy groups in the states we visited provided supports to the families of young adults with ASD. Family education and supports is another service area we previously identified that may be needed to assist youth in the transition to adulthood.⁴⁹ For example, one non-profit in New Jersey hosts a transition fair annually and maintains a referral database on its website to help families identify supports including transition and adult services. A non-profit organization in Phoenix, Arizona, holds monthly meetings for transition-age youth and their parents with speakers on various topics, such as financial planning, sexual education, and disability resources for college. The organization also provides individual assistance to families for how to apply for services and benefits as they transition to adulthood, such as Social Security benefits. Other adult service providers we interviewed reported offering in-home supports to family members or workshops for families.

A few adult service providers we interviewed told us they taught safety skills to individuals with ASD as part of their independent living and vocational training programs. One provider taught clients how and when to call 911, how to store food properly, and about sexual education. Parents and family members of transition-age youth in three of our five discussion groups expressed concern for the safety of their young adults, including interactions with law enforcement. For example, one father in a New Jersey discussion group worried about whether law enforcement officers would interpret his son's literal answers to questions as being disrespectful or defiant. Staff we interviewed at a service provider in South Carolina reported they offer training for law-enforcement and first responders on how to identify signs that an individual has ASD and how to interact with these individuals.

⁴⁹[GAO-17-109](#).

Untimely Transition Planning, Complex Adult Systems, and Few Employment Opportunities Are Key Challenges to Transitioning to Adult Life, According to Stakeholders

Transition Planning Sometimes Occurs Too Late to Meet Students' Needs, According to School Districts, Service Providers, and Others

IDEA currently requires schools to include in the IEP transition services needed to assist youth in reaching their appropriate measurable postsecondary goals no later than the first IEP in effect when students reach age 16.⁵⁰ According to our analysis of school districts' survey responses, almost all school districts reported beginning transition planning for students by age 16.⁵¹ However, the majority of school districts surveyed (an estimated 72 percent) reported that age 14, or younger, would be the most beneficial age to begin transitioning students to adult life. Our estimates from school districts' survey responses indicate that approximately 32 percent of districts—which represents about 4,000 school districts—begin transition planning when students are older than age 14. By not starting transition planning until after age 14, these districts—covering more than 1 million students with disabilities⁵²—may not be providing youth with the additional time needed to build the

⁵⁰One purpose of IDEA is “to ensure that all children with disabilities have available to them a free appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment, and independent living.” 20 U.S.C. § 1400(d)(1)(A). Transition services may begin before the age of 16 if the IEP team determines it is appropriate to do so, or if state law requires transition planning to begin earlier than age 16.

⁵¹According to IDEA, the U.S. Department of Education is to review states' compliance with the IDEA transition services requirement through states' annual performance reports. We did not assess state or school district compliance with IDEA as part of this review.

⁵²This estimate represents the lower bound of the 95 percent confidence interval for the estimated total number of students with disabilities in districts that begin transition planning when students are older than age 14 and has a relative error of about +/- 30 percent.

skills for adult life, and the time for schools, parents, and service providers to develop IEPs that align with the goals and needs of youth transitioning out of school.

Transition Planning Services: Example of Key Service Needed to Support Transitioning Youth with Autism

In one school district, officials we interviewed said they start transition planning in middle school with conversations with the student and family about their interests. Officials said that once the student reaches high school the transition planning meetings become the driving force of the individualized education program. They conduct assessments of the student and use online tools to explore the career options that match the student's interests and needs.

Source: GAO interview. | GAO-17-352

The views of many school districts regarding earlier transition planning is consistent with the view of several stakeholders we interviewed, as well as panelists we talked to in our prior work who said that beginning transition planning before age 16 would be the most beneficial for students.⁵³ Stakeholders said that beginning transition planning at an earlier age, with age 14 or younger being commonly cited in our survey and multiple interviews, can have many benefits. School officials we spoke with explained that earlier transition planning allows families more time to apply for and secure services in the adult system before a student leaves the school system.

According to Education officials, the agency does not have the authority, without statutory revisions to IDEA, to change the age requirement for beginning transition services and has not asked Congress for the authority to do so. Education officials reported that IDEA currently provides states and districts with the ability to provide transition services earlier if so desired. In guidance since at least 2007, and again in January 2017, Education restated IDEA requirements that by age 16, students' IEPs must address the transition services requirement, and that IEP teams can provide transition services earlier if determined appropriate. Education officials also stated they considered age 14 too early for some middle school age students to begin transition planning because students may lack the experience and educational development to make decisions about future life choices.

However, providing discretion in this area may not serve some students well, according to stakeholders we interviewed. Based on our nationally generalizable sample of public school districts, we identified at least 29 states that had one or more school districts that do not start transition planning until the age of 16 or older.⁵⁴ Our prior work and stakeholders we interviewed also reported that starting transition planning at age 16

⁵³GAO-17-109.

⁵⁴Because this analysis is based on the results of a sample of school districts that was not designed to be representative at the state level, it is possible there are school districts in additional states that do not start transition planning until the age of 16 or older.

may be too late.⁵⁵ For example, by age 16, students with ASD may be in their junior year of high school, and many students interested in college need to be positioning themselves to meet college admissions requirements before that point. Consistent with findings from our school district survey, an official from an organization representing school district officials stated that it is good practice to begin conversations about transition at or before the beginning of high school, to ensure that students secure the coursework needed to meet graduation and other requirements, and that most districts already do so. In addition, research has shown that some of the most typically at-risk students—low-income youth and African-American youth—receive transition planning later than other youth.⁵⁶ Although Education funds research on transition planning for students with disabilities, Education currently does not fund research evaluating the appropriate age to begin transition planning.⁵⁷

Education guidance specifically identifies taking an appropriate preparatory curriculum in high school as critical for success in postsecondary education, stating that students with disabilities need to make high school curriculum choices that support the goal of postsecondary education. Early planning also allows more time to ensure that youth obtain the work, community, and academic experiences needed to successfully transition to adult life. For example, one district reported that it lowered its transition planning age to 14 so that youth had more time to gain valuable work experience by sampling different types of jobs in the community. Further, lowering the IDEA transition age could expose students to employment-related services sooner because transition services and pre-employment transition services through the

⁵⁵GAO, *Students with Disabilities: Better Federal Coordination Could Lessen Challenges in the Transition from High School*, [GAO-12-594](#) (Washington, D.C.: July 12, 2012) and [GAO-17-109](#).

⁵⁶Roux et al.

⁵⁷According to Education officials, through the Institute of Education Sciences National Center for Special Education Research, since 2006, Education has funded 29 research grants related to transition planning for students with disabilities representing an investment of about \$53 million, and includes the development of online tools for use by IEP teams in developing transition goals for students with disabilities.

VR program are provided to students with disabilities using the IDEA transition age requirements.⁵⁸

The 2004 IDEA reauthorization increased the age of the transition services requirement for students with ASD, as well as for youth with other disabilities, from age 14 to age 16. The legislative history of the 2004 reauthorization of IDEA does not fully explain why this change was made.⁵⁹ During the 2006 public comment period for the current IDEA regulations on transition services, many commenters disagreed with changing the transition age from 14 to 16, and a few specifically requested that Education consider beginning transition services before age 16.⁶⁰ In 2013, public commenters responding to the Federal Partners in Transition's (FPT) national online dialogue identified lowering the transition age as a top idea for addressing regulatory or legislative barriers for youth.⁶¹ The Advisory Committee on Increasing Competitive Integrated Employment for Individuals with Disabilities, which was established to help advance competitive employment opportunities for individuals with intellectual disabilities, developmental disabilities, or other significant disabilities, also recommended that Congress amend IDEA to lower the transition age for all students with significant disabilities to begin

⁵⁸A student with a disability must meet age and program requirements to be eligible to receive transition services or pre-employment transition services under the Rehabilitation Act, as amended by WIOA. Under the Act, students with disabilities are not younger than the earliest age for the provision of transition services under IDEA or, if the State elects to use a lower minimum age, not younger than that minimum age. 29 U.S.C. § 705(37).

⁵⁹Education officials said they reviewed the legislative history and noted that in order to reduce confusion among parents and school districts the 2004 reauthorization consolidated two separate age requirements for the IEP – one for “transition service needs” and the other for “needed transition services”—into one age standard for both transition planning and services, i.e. age 16. Education official said that the legislative history does not explain why Congress chose age 16 over 14.

⁶⁰In response to these comments, Education included the phrase “or younger if determined appropriate by the IEP team” in 34 C.F.R. § 300.320(b), which generally discusses transition services required in the IEP. However, in the same response, Education reiterated that the agency could not require that IEPs include transition planning or assessments, as it is beyond what is specifically required in the Act.

⁶¹Staff from Education, HHS, DOL and SSA formed the Federal Partners in Transition (FPT) interagency workgroup in 2005 to improve interagency coordination around transition-aged youth issues. The FPT seeks to support all youth, including youth with disabilities, in successfully transitioning from school to adulthood. Concepts, Inc., Federal Partners in Transition National Online Dialogue Participation Metrics Final Report (September 23, 2013).

at 14 or earlier.⁶² Panelists we spoke to for our prior work also suggested that transition planning should start earlier—as early as middle school—and cited research noting that any gaps or loss of services during the transition from a school-based support system to adulthood could have long-lasting detrimental effects on youths’ health, employment, educational attainment, and family stability.⁶³

Families, Service Providers, and Advocates Reported That Adult Systems and Services Are Often Difficult to Navigate and Access

Navigating Service Systems

Stakeholders, including parents, service providers, and advocates, cited challenges in navigating the transition from the public school system to adult service systems and accessing needed services.

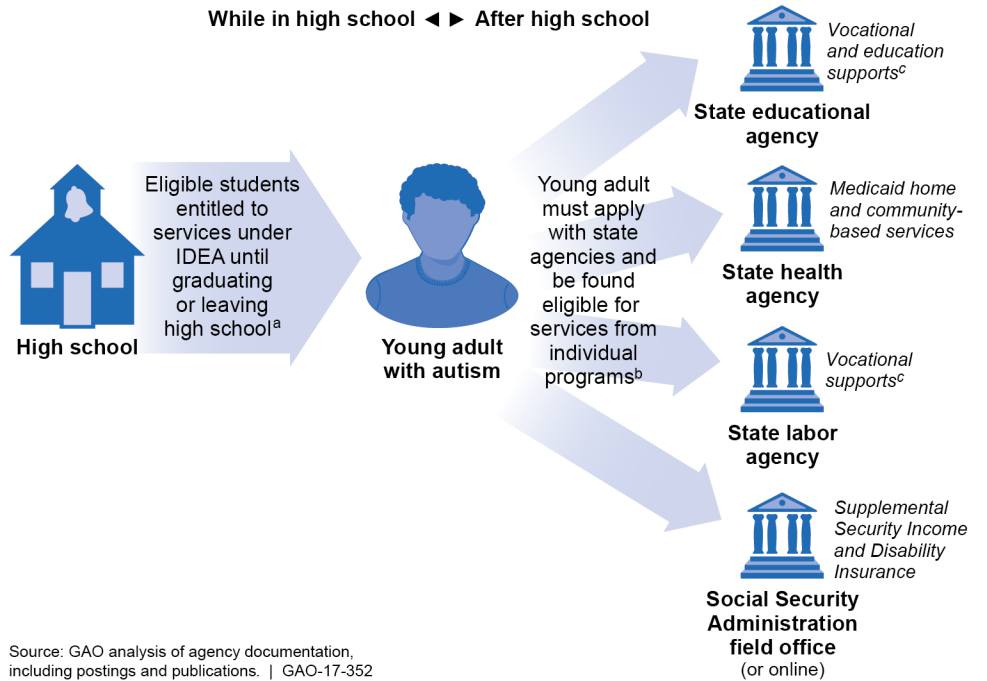
According to parents and other stakeholder, youth with disabilities, including those with ASD, and their families often face challenges navigating the complex adult service systems after exiting from school, which is consistent with our prior work (see fig. 6).⁶⁴ For example, about 70 percent of school districts surveyed identified “lack of assistance navigating the (adult) service systems” as a challenge for youth with ASD trying to obtain needed services and supports once they leave high school. Further, many district officials and teachers we interviewed expressed doubts that students with ASD would be able to obtain the necessary services and supports outlined in their final transition plan after they exit the school system.

⁶²The Advisory Committee on Increasing Competitive Integrated Employment for Individuals with Disabilities Final Report (September 15, 2016). WIOA created the Advisory Committee on Increasing Competitive Integrated Employment for Individuals with Disabilities composed of several federal and non-federal stakeholders to provide recommendations on ways to increase competitive employment opportunities for people with intellectual or developmental disabilities or other individuals with significant disabilities, as well as the use and oversight of the certificate program as carried out under Section 14(c) of the Fair Labor Standards Act of 1938.

⁶³[GAO-17-109](#).

⁶⁴See [GAO-12-594](#); GAO, *Young Adults with Serious Mental Illness: Some States and Federal Agencies Are Taking Steps to Address Their Transition Challenges*, [GAO-08-678](#) (Washington, D.C.: June 23, 2008); GAO, *Summary of a GAO Conference: Helping California Youths with Disabilities Transition to Work or Postsecondary Education*, [GAO-06-759SP](#) (Washington, D.C.: June 20, 2006); and GAO, *Special Education: Federal Actions Can Assist States in Improving Postsecondary Outcomes for Youth*, [GAO-03-773](#) (Washington, D.C.: July 30, 2003).

Figure 6: Students Move from Services Provided through Their High Schools to Services Delivered through Multiple Programs



Source: GAO analysis of agency documentation, including postings and publications. | GAO-17-352

^a Students remain eligible for transition planning and services, as well as other special education services, until they graduate from high school with a regular high school diploma or exceed the earlier of age 21 or the eligibility age for a free appropriate public education under state law. While federal law authorizes students to receive a free appropriate public education up until age 22, eligibility for students aged 18 and older is determined by states. 20 U.S.C § 1412(a)(1) and 34 C.F.R. § 300.102(a).

^b Students with disabilities do not need to apply to receive Vocational Rehabilitation (VR) pre-employment or group transition services.

^c States may choose to provide VR program services under their state educational, labor, or health and human services agencies.

**Case Management and Coordination:
Example of Key Service Needed to
Support Transitioning Youth with
Autism**

In Arizona, a federally funded grant pilot program provides case management to assist young adults and families with navigating adult service programs, processes, and requirements across state agencies. According to program officials, the case managers serve as an overall connecting piece for young adults and families, providing them with information on community resources, training on self-advocacy, as well as referrals to adult service agencies.

Source: GAO interview. | GAO-17-352

Stakeholders and parents in two of our five discussion groups reported that parents often are not aware of, or do not know how to access, the adult services available to them after exiting the school system. As one provider and parents we spoke with explained, parents of young adults with ASD may not have the time or knowledge needed to successfully navigate the multiple adult care agencies and paperwork, due to other responsibilities such as full-time jobs or additional children. Parents and family members in all five discussion groups described some of these difficulties navigating adult systems. For example, in one discussion group, a parent of a young adult reported that she had to work with nine different state agencies to obtain needed services, including housing and behavioral management services, and she only learned how to do so by speaking with other parents and following email listservs. In another discussion group, a family member reported that her sister was assigned to at least three service coordinators from the state developmental disabilities agency before receiving a coordinator who was willing to research and follow up on services that aligned with her needs.

**Access and Availability of Adult
Services**

In addition to the challenge of navigating a complex system of services, parents, providers, and experts we interviewed described the challenge of access and availability of adult services, which affect the ability of youth with ASD to attain their goals for adulthood. Specific concerns we heard include: waiting lists for services, lack of service options available, lack of trained providers, and cost of services.

Waiting lists. Developmental disabilities councils in all three states in our review cited waiting lists as a challenge to receiving services. Specifically, South Carolina and New Jersey had waiting lists for at least some developmental disabilities services, and Arizona had a waiting list for VR services. According to an Arizona official, the state groups individuals on the list using three “priority groups”; however, two of the three groups have been effectively closed since 2009 because of resource constraints.⁶⁵ In South Carolina, state officials reported that individuals will likely face a waiting list once they are determined eligible for developmental disabilities services. While waiting lists in this state are operated on a first come first serve basis, officials estimated that individuals can wait up to 3 years to receive services. Youth with ASD

⁶⁵In cases in which a VR agency is unable to provide services to all eligible applicants due to capacity constraints (e.g., limited fiscal and/or personnel resources), the VR agency is required to prioritize service provision to individuals with the most significant disabilities and implement an “order of selection.”

who exit the school system and then go without services for a period of time may experience detrimental effects in the future, such as losing progress made on skill development, according to stakeholders and our recent work.⁶⁶ Parents in four of five discussion groups also reported waiting lists for housing. One parent reported that there is currently a 10- to 12-year wait for supportive housing. Parents in our discussion groups noted that the lack of housing options in general was particularly concerning since parents may become unable, either through aging or poor health, to care for their children with autism.

Mental Health Care: Example of Key Service Needed to Support Transitioning Youth with Autism

Arizona state officials said the state provides behavioral health services to assist clients with their mental health stability and community integration, and to help them obtain and maintain their employment goals.

Source: GAO interview. | GAO-17-352

Lack of service options. While there are multiple adult service systems available, parents in discussion groups, multiple providers, and our recent work cited lack of service options available to young adults with ASD and their families. Family members in one discussion group reported that adult service programs sometimes combine groups with very different needs—that is, by serving low-needs and high-needs individuals at the same time—which could be challenging for both groups, or they combine a wide range of ages together for services. In addition, a lack of providers can limit service options in rural areas. For example, in South Carolina, a hospital closure in a rural area meant that individuals had to travel further to get health care, and in some parts of the state there is only one state developmental disabilities provider available. Our recent work also highlighted the need for youth with autism to receive timely access to services and supports, including having enough service providers to meet the demand.⁶⁷ Further, as roundtable panelists in our recent work also noted, girls and minority students are diagnosed with ASD at a later age than other youth, on average, which could delay needed services while in school.⁶⁸ A lack of service options may be a challenge for transition-age youth with disabilities more broadly—in 2015, the FPT highlighted as a policy priority the need to expand service opportunities, such as internships and other training options, for transition-age youth with disabilities.⁶⁹

⁶⁶GAO-17-109.

⁶⁷GAO-17-109.

⁶⁸GAO-17-109.

⁶⁹Federal Partners in Transition Workgroup, *The 2020 Federal Youth Transition Plan: A Federal Interagency Strategy* (February 2015).

Medical Care: Example of Key Service Needed to Support Transitioning Youth with Autism

At one nonpublic school we visited, the health office is set up like a doctor and dentist office and the nurses wear scrubs, to help familiarize students with being at a doctor or dentist office.

Source: GAO interview. | GAO 17 352

Behavioral Interventions: Example of Key Service Needed to Support Transitioning Youth with Autism

A New Jersey state official said the state provides intensive supports to help stabilize families in crisis situations, such as when families do not know how to handle their youth's challenging behavior. According to the official, youth in these situations receive the agency's intensive short-term supports while staying in their home school, with the goal of ensuring the youth is able to continue living at home.

Source: GAO interview. | GAO-17-352

Lack of trained providers. According to multiple adult service providers and parents, there are few providers trained to work with young adults with ASD. As one health provider explained, doctors may not receive training, in medical school or otherwise, on how to correctly interpret and manage potentially disruptive behaviors in an adult patient with ASD during an exam, including proper use of sedation as needed. Further, in 2015 the FPT identified supporting professional development for service providers, including job coaches and health care providers, as a policy priority to improve transition outcomes for youth with disabilities seeking competitive employment.⁷⁰ In 2016, the federal Advisory Committee on Increasing Competitive Integrated Employment for Individuals with Disabilities also reported that service providers needed more training to support individuals with significant disabilities seeking competitive employment.⁷¹

Similarly, in our review, multiple advocates and providers reported that vocational and other service providers need more training on how to work with young adults with ASD. Providers, as well as a state VR official and an advocacy group, also noted that VR counselors may have a disincentive to learn how to work with individuals with ASD because these young adults may need more assistance to attain and sustain employment. Multiple providers also reported difficulties with retaining staff, at times due to low rates of state payments for providers' services, which can contribute to lower staff salaries overall. Our recent work also noted that youth with autism may have difficulty developing new relationships with service providers and can be negatively affected by high turnover rates.⁷²

Cost of services. Parents of young adults with ASD and providers also reported that the cost of services can be a challenge as youth transition to adult life. For example, a rural provider reported that youth may wait 6 to 18 months to receive a diagnosis, a qualifying requirement for that state's developmental disabilities services, and teachers in one district observed that some families pay as much as \$6,000 to have an examination for the diagnosis. Because autism is highly individualized, young adults with ASD frequently require an individualized program of services that can be

⁷⁰Federal Partners in Transition Workgroup, *The 2020 Federal Youth Transition Plan*.

⁷¹The Advisory Committee on Increasing Competitive Integrated Employment for Individuals with Disabilities Final Report (September 15, 2016).

⁷²[GAO-17-109](#).

expensive, according to one provider. The IACC has also highlighted research on the costs associated with certain services provided to individuals with ASD, such as vocational services.⁷³ This issue was also identified by our roundtable participants. Panelists in our prior work reported that low- and middle-income youth with ASD whose families cannot afford to pay for services out-of-pocket may not always be able to rely on public programs to help them pay for their adult services.⁷⁴ Parents in two of our discussion groups noted that needed adult services can be beyond the family's ability to pay. For example, one parent and our prior work reported that moving from school services to adult services can feel like falling off a cliff. Another parent reported that the primary autism-specific provider in her area does not accept state developmental disability funding or regular insurance, and most families cannot afford to pay out-of-pocket. One advocate also noted that local transitional living programs' costs are higher than what the families she worked with could cover. Several providers noted that state reimbursement rates did not align with actual provider expenses. Cost of services may also contribute to some of the challenges previously mentioned, such as lack of service options and trained providers.

Youth Face Lack of Employment Opportunities and Related Supports, According to Districts Surveyed and Others

After young adults with ASD transition to adult life, they may encounter challenges similar to other young adults with disabilities, such as securing employment, housing, and transportation. We estimate that a majority of school districts consider a lack of employment options to be a top challenge to providing transition services across youth with ASD with low-, moderate-, and high-intensity service needs (ranging from 73 to 88 percent, respectively). In addition, we estimate that over one-quarter of school districts also reported that both job coaching and work experiences were difficult to provide to individuals with ASD.

Similarly, stakeholders we interviewed reported that youth with ASD face unique challenges to securing employment. For example, teachers at one high school told us that there are limited opportunities to provide work experiences for youth with ASD due to potential employers' lack of exposure to autism, fears around the extent of job-related supports

⁷³Interagency Autism Coordinating Committee (IACC), 2015 IACC Summary of Advances in Autism Spectrum Disorder Research (April 2016).

⁷⁴[GAO-17-109](#).

Communication Services: Example of Key Service Needed to Support Transitioning Youth with Autism

In one nonpublic high school serving students with Autism Spectrum Disorder (ASD), we observed a literature class in which the students used tablets to answer questions in writing posed by the teacher as a way to engage students who have difficulty expressing themselves through verbal communication. The teacher asked a question and the students' answers would appear on the large screen at the front of the room.

In another nonpublic high school for students with ASD, we observed non-verbal students working in the canteen using voice recognition systems through tablets to have conversations with customers.

Source: GAO observations from facility tours. | GAO-17-352

Transportation Services: Example of Key Service Needed to Support Transitioning Youth with Autism

One service provider in Phoenix, Arizona offers a new 2-year program designed for young adults age 18 and older that was designed to be in close proximity to public transportation to help residents get to work. Students attend a local community college and take courses on independent living topics, including how to use transportation.

Source: GAO interview. | GAO-17-352

needed, and lack of financial incentives for employing youth with autism or other disabilities. Some stakeholders said that employers may not understand that individuals with ASD can be valuable employees or know how to create an environment where they can thrive. The employers we interviewed that have specific efforts to hire individuals with ASD highlighted the importance of educating managers about ASD and how best to interview, support, and utilize an employee with ASD. Similarly, panelists in our prior work also discussed providing employers with information about hiring and working with autistic employees, as a support associated with successful employment of individuals with autism.⁷⁵

In addition to securing work, stakeholders reported that youth with ASD face challenges to obtaining the supports needed to sustain employment, such as reliable transportation and job coaching. For example, one state official noted that transportation may be a challenge to maintaining employment for individuals with ASD, particularly in rural and suburban areas, due to limited public transportation options. Our prior work also noted that limited access to reliable transportation to and from employment programs and services providers, especially in rural areas, was a major challenge for students with disabilities.⁷⁶ Similarly, an estimated 69 percent of school districts identified lack of transportation as a factor that would negatively affect the ability of youth with ASD to obtain needed services and supports. Stakeholders also reported that eligibility and timely access to job coaching was another challenge. Our prior work also noted that while some programs may teach youth with ASD how to interview for a job, youth also need to learn about navigating the social aspect of employment and may require ongoing support in this area.⁷⁷

⁷⁵GAO-17-109.

⁷⁶GAO-12-594.

⁷⁷GAO-17-109.

Federal Collaborative Efforts Have Missed Opportunities to Enhance Support of Transition-age Youth with Autism

The Interagency Autism Coordinating Committee Has Not Regularly Engaged Key Federal Agencies That Support Youth with Autism

The IACC, managed by HHS, has facilitated collaboration across its member federal agencies on research related to individuals with ASD, including transition-age youth, but it has not regularly engaged several key federal agencies that serve transition-age youth with ASD.⁷⁸ In particular, the IACC has collaborated on transition-age issues for youth with autism by inviting researchers to present their findings related to transition-age youth during meetings and including research related to this population in its strategic plan and portfolio analysis (for more information on research needs related to transition-age youth, see app. II). However, IACC has missed opportunities to collaborate with non-member federal agencies to report on and monitor services and supports activities for individuals with ASD, which Congress has called for IACC to include in its annual strategic plan and monitoring activities.⁷⁹ HHS officials reported that the IACC plans to begin including some services and supports information in its next strategic plan, which it expects to release in early or mid-2017.⁸⁰ However, HHS officials told us that the IACC has not engaged certain key federal agencies with responsibility for

⁷⁸Within HHS, the National Institutes of Health (NIH) Office of Autism Research Coordination (OARC) provides assistance to IACC through coordination and management of IACC-related activities.

⁷⁹The Autism CARES Act has required the IACC to include in its annual strategic plan and in its monitoring activities, to the extent practicable, services and supports for individuals with ASD. Autism CARES Act of 2014, Pub. L. No. 113-157, § 5, 128 Stat. 1831, 1832-33. The most recent IACC annual strategic plan, the 2013 update, was published in April 2014.

⁸⁰In response to the Autism CARES Act requirement that the IACC strategic plan include budgetary estimates for services and supports to the extent practicable, HHS officials said that they may delay the inclusion of budgetary estimates for services and supports until the subsequent IACC strategic plan. With regard to the expanded responsibility to monitor services and supports activities for individuals with ASD to the extent practicable, HHS officials said that the IACC would not determine the approach it will use for meeting this requirement until the update of the IACC strategic plan is completed.

...serving or providing financial assistance to populations including transition-age youth with ASD to gather their input on the content of the plan, nor has it invited such agencies to serve on the committee.⁸¹ The Autism CARES Act authorizes the Secretary of Health and Human Services to include other federal agencies that serve individuals with ASD as members of the IACC. While, according to HHS officials, the IACC welcomes engagement with agencies interested in focusing attention on issues related to autism, they said that the department would not reach out to federal agencies for potential membership unless such agencies expressed interest and that few agencies have done so.⁸² For example, when we asked SSA officials if they had considered requesting membership on the IACC, they told us that although they had not previously considered it, as of January 2017, they were planning to do so. On April 26, 2017, the IACC announced SSA as a new member. Similarly, when we asked DOL officials the same question, they told us they had not previously considered it, but that in the future they would look for additional opportunities to work with the IACC. They further stated that the agency will contact the IACC to determine interest in working on employment issues.⁸³

DOL, HUD, and SSA manage programs and research that serve or provide financial assistance to populations including transition-age youth with disabilities, including youth with ASD, which potentially provides those agencies with experience, expertise, and unique viewpoints that could benefit the work of the IACC. For example, DOL provides grants to states through the Disability Employment Initiative to improve effective and meaningful participation of transition-age youth and adults with

⁸¹DOL and HUD are examples of federal agencies that could be considered for IACC membership; we did not explore whether agencies not included in our review should be considered for IACC membership. Our review identified two instances in which an official from one of these agencies presented at an IACC meeting since November 2015, which was the first meeting of the current IACC. Specifically, an official from DOL presented on the Advisory Committee on Increasing Competitive Integrated Employment for Individuals with Disabilities during the April 2016 and April 2017 IACC meetings. However, the IACC has not engaged non-member agencies for input on its strategic plan.

⁸²According to HHS officials, the EPA requested membership on the IACC in 2015 and was subsequently added.

⁸³A DOL official stated that the agency has been in contact with the Department of Education Rehabilitation Services Administration regarding business community interest in, and business developed tools to work with, individuals with ASD to share resources. DOL officials also stated that the agency provides funding for the Job Accommodation Network that has created technical assistance resources related to individuals with ASD.

disabilities in the workforce system. Additionally, in 2014 SSA completed the Youth Transition Demonstration evaluation which sought to identify and test the most promising service strategies to enhance work incentives for helping youth with disabilities maximize their economic self-sufficiency as they transition to adulthood.⁸⁴ In past strategic plans, the IACC specifically identified research needs related to employment, community housing, and Social Security programs, which are areas within DOL, HUD, and SSA's purview. Further, during an IACC working group conference call in November 2016, some members of an IACC working group tasked with updating the lifespan and transitions area for the strategic plan suggested that HHS invite representatives of federal agencies who serve transition-age youth and adults to join the IACC to better inform development of the strategic plan.⁸⁵ However, thus far there have been no representatives from DOL, HUD, or SSA on any of the working groups tasked with updating the current IACC strategic plan.

There is precedence for these agencies collaborating in support of youth with disabilities. DOL, HUD, SSA, and Education are part of a joint research grant initiative called the Promoting the Readiness of Minors in Supplemental Security Income (PROMISE) that focuses on improving the life outcomes of youth with disabilities by supporting improved coordination of services.⁸⁶ One of the leading federal practices for effective collaboration stresses the importance of ensuring that all relevant participants are included in collaborative activities as efforts can be limited when they do not have the right agencies fully engaged.⁸⁷ Unless HHS finds ways to regularly engage certain non-member federal agencies that serve or provide financial assistance to populations

⁸⁴Mathematica Center For Studying Disability Policy, *Final Report on the Youth Transition Demonstration Evaluation* (November 2014)

⁸⁵Recently, some members of this IACC working group specifically requested that federal agencies, such as HUD, the Department of Transportation (DOT), and DOL, be potentially added as IACC member agencies. The lifespan and transitions area is one of seven general topic areas of the IACC strategic plan.

⁸⁶The PROMISE program is a joint initiative administered by Education. According to Education officials, under the PROMISE program, states have developed partnerships and are implementing coordinated services, supports, and interventions to project participants. Additionally, according to officials, in fiscal year 2013, Education awarded 5-year model demonstration research projects to five states and a consortium of six states to improve the education and employment outcomes of children receiving SSI and their families.

⁸⁷[GAO-12-1022](#).

including individuals with ASD, including transition-age youth, the IACC may miss the opportunity to leverage the knowledge of other agencies as it works to fulfill its expanded responsibilities under the Autism CARES Act. In particular, it may inhibit its ability to create an up-to-date strategic plan that includes comprehensive and accurate information on research and services that can be used to advance research and services that aim to improve the health and well-being of individuals with ASD.

The Federal Partners in Transition Identified Priorities to Support Transition-age Youth but Lacks Plans for Implementation

As part of the Federal Partners in Transition (FPT), Education, HHS, DOL, and SSA have collaborated to identify priorities for supporting transition-age youth with disabilities, but they have not consistently followed leading collaboration practices to implement these priorities. As part of its 2020 plan,⁸⁸ the FPT established several priorities for federal action including:⁸⁹

- promoting work-based learning,
- supporting professional development for service providers,
- bridging the service gap between youth and adult programs,
- demonstrating the value of hiring youth and young adults with disabilities, and
- improving education and outreach to the public regarding policy and practices governing transition programs.

Since identifying these priorities in the plan, the FPT has not developed a comprehensive strategy for how these priorities will be carried out. To achieve mutually agreed upon outcomes, one leading collaboration practice calls for establishing mutually reinforcing or joint strategies,⁹⁰ such as through developing a comprehensive strategy for accomplishing goals, which would include specific actions to implement plans. For example:

- The FPT's yearly action plan describes the activities it will address and policy priority areas it will focus on for an individual year, but the

⁸⁸Federal Partners in Transition Workgroup, *The 2020 Federal Youth Transition Plan*.

⁸⁹In response to our recommendation in 2012 the FPT released a strategic plan to enhance interagency coordination and improve the outcomes for youth with disabilities by 2020. See [GAO-12-594](#).

⁹⁰[GAO-06-15](#).

plan does not include a long-term strategy to ensure progress is made on each priority area through 2020. Further, while the FPT establishes some timelines for deliverables and includes activities for some of the goals and policy priority areas, it does not establish timelines, milestones, or deadlines for making progress toward each of the goals and policy priority areas. Other leading collaboration practices are to clearly define short-term and long-term outcomes and to track and monitor progress toward these outcomes.⁹¹

- The FPT has not assigned roles and responsibilities among the member agencies or taken steps to make agencies responsible for particular outcome goals or policy priority areas.⁹² According to DOL officials, the FPT is a voluntary effort among member agencies to enhance coordination and does not have authority to compel member agencies to take action. However, another leading collaboration practice is to clarify and agree on the roles and responsibilities of each agency involved in a collaborative effort. Other agencies involved in collaborative efforts have addressed this in various ways, such as by implementing mutually reinforcing or joint policies—or a memorandum of understanding—that clarify roles and responsibilities.⁹³

Representatives of the FPT and member agencies stated that resource constraints make it difficult to effectively collaborate and coordinate across the federal agencies.⁹⁴ However, we previously reported that, according to the Office of Management and Budget (OMB), agencies generally do not receive specific funding for interagency activities.⁹⁵ We have also reported on strategies to leverage resources for interagency efforts, such as developing an inventory of relevant resources, which can result in better leveraging of resources. Although FPT has taken some

⁹¹[GAO-12-1022](#).

⁹²Representatives of the FPT stated that a specific agency may volunteer to take the lead on a particular effort, but that in general member agencies have not volunteered to take responsibility for particular efforts.

⁹³[GAO-12-1022](#).

⁹⁴In addition, representatives of the FPT and member agencies stated that the FPT has no designated staff or specifically appropriated funds for its activities. According to officials from some of the member agencies, staff who do related work are utilized for FPT activities in addition to the staff's normal duties.

⁹⁵GAO, *Managing for Results: Implementation Approaches Used to Enhance Collaboration in Interagency Groups*, [GAO-14-220](#) (Washington, D.C.: Feb. 14, 2014).

steps toward collaboration, without a long-term implementation plan that includes milestones and specific agency roles and assignments, it is less likely that the FPT will implement and accomplish the five compatible outcome goals and 12 policy priorities for future strategic focus by the 2020 Plan's stated timeline.

The Extent of Collaboration under Recent Autism CARES Act Requirements Has Been Limited

Youth Transition Report

In addition to IACC, the Autism CARES Act required HHS to lead two collaborative efforts in support of transition-age youth with ASD, but federal agencies' efforts to address these requirements are currently limited.

HHS is coordinating with other federal agencies to prepare a report on transition-age youth with ASD, but HHS officials told us that they did not meet the statutory deadline of August 2016 and will not be able to include all of the report elements required by the Autism CARES Act in the report due to resource constraints and the timing of the appointment of the Autism Coordinator.⁹⁶ The Act requires HHS to coordinate with certain federal agencies to develop a report containing, among other things, proposals for best practices guidelines to ensure coordination among relevant service providers and comprehensive approaches to transitioning from existing school-based services to those services available during adulthood. According to the Autism Coordinator and other HHS officials, HHS has established a steering committee composed of representatives of various federal departments, including Education, Department of Transportation (DOT), DOL, the Department of Justice (DOJ), and HUD, as required by the Act, and has requested information from other federal departments, including DOD, for inclusion in the report. HHS officials have reported that HHS currently plans to finalize and submit the report to Congress by April 2017. According to the Autism Coordinator and other HHS officials, due to resource constraints, the report will be limited to describing current activities at HHS and other federal departments with respect to transition-age youth with ASD, gaps in federal programs, and research needs and recommendations on ASD and transition issues.

⁹⁶The Autism Coordinator was not appointed until April 2016 and the Youth Transitions Report was due in August 2016 per the Autism CARES Act.

Autism Coordinator

As we previously reported, in April 2016 the Secretary of HHS designated an official as the Autism Coordinator⁹⁷ in response to a requirement contained in the Autism CARES Act to oversee and implement federal ASD activities nationwide and ensure that federal ASD activities are not unnecessarily duplicative.⁹⁸ Since that time, the Coordinator has taken some steps to fulfill the responsibilities required by the Act, including leading the agency's efforts to prepare the report on transition-age youth, according to HHS officials.⁹⁹ In addition, according to the Autism Coordinator and other HHS officials, the official has received information from and reviewed ASD activities across HHS, Education, DOL, DOJ, DOT, DOD, HUD, and SSA. However, the Autism Coordinator and other HHS officials told us that the Coordinator would have limited capacity going forward to oversee ASD work across agencies and departments as required by the Act due to limited resources. Because the position was recently filled, it is too early to assess the Coordinator's efforts toward meeting the requirements. It is therefore unclear whether HHS will meet the requirements to oversee and implement ASD activities or enhance coordination of ASD activities across federal agencies.

Conclusions

For many youth with ASD, the transition to adulthood begins with an IEP that specifies the transition services needed to reach their measurable postsecondary goals and must be in effect no later than age 16, as required by IDEA. However, as our work and other research has shown, starting transition planning at 16 may be too late for many youth. Recent federal efforts have highlighted the need for transition planning to begin earlier than 16 for ASD youth. Our school district survey and stakeholders suggest that earlier transition planning can have multiple benefits, including providing the necessary education, work, and community experiences needed to successfully transition to adult life. Currently,

⁹⁷In 2013, we recommended that to promote better federal coordination and avoid unnecessary duplication, certain federal agencies, including HHS, should determine methods for identifying and monitoring the autism research conducted by other agencies ([GAO-14-16](#)). In a follow-up report in 2016, we found that HHS had begun taking steps to implement the Autism CARES Act, such as designating an Autism Coordinator that could help coordinate federal autism research. GAO, *Federal Autism Activities: Agencies Are Encouraging Early Identification and Providing Services, and Recent Actions Could Improve Coordination*, [GAO-16-446](#) (Washington, D.C.: May 20, 2016).

⁹⁸Autism CARES Act of 2014, Pub. L. No. 113-157, § 2, 128 Stat. 1831, 1831.

⁹⁹To see our recommendation follow up for our November 2013 report: <http://www.gao.gov/products/GAO-14-16>.

many students are not getting the opportunity to take advantage of these benefits, potentially further exacerbating gaps in college and work readiness. Further, although this report focuses on transition-age youth with ASD, stakeholders we interviewed indicated that earlier transition planning would likely be beneficial for other students with disabilities. Unless Education examines the outcomes for students who begin transition services at age 16 and the merits and implications of requiring earlier transition planning for all students with disabilities, policymakers may not have critical information when considering changes to IDEA.

Multiple federal collaborative entities, including the IACC and FPT, have identified gaps in research or services for transitioning youth and young adults with ASD. While the IACC has focused on coordinating research on individuals with ASD, federal law has recently called for the IACC to also report on and monitor services for adults, including transition-age youth. Given the increased scope of IACC's responsibilities and per leading federal interagency collaboration practices, the IACC needs to regularly engage key federal agencies—such as DOL and HUD—that provide services or financial assistance to adults with ASD. Without such efforts, the IACC strategic plan may not include important information that these agencies have such as on services and supports, as well as potentially miss opportunities to identify critical gaps in these areas. Likewise, the FPT has helped to address the challenges facing transition-age youth with disabilities, including those with ASD, by identifying priority areas for federal action in its 2020 plan. While a positive initial step, without implementing milestones or assignments to move these priorities forward in line with leading federal interagency collaboration practices, it is less likely that these priorities will be achieved.

Recommendations for Executive Action

To determine whether IDEA's current transition age requirement allows youth with disabilities, including those with ASD, the time needed to plan and prepare for the transition to adult life, the Secretary of Education should examine outcomes for students when transition services begin at age 16 and the merits and implications of amending IDEA to lower the age at which school districts are to begin providing transition services to students with disabilities, such as 14.

To improve collaboration and leverage the knowledge of key federal agencies serving youth with ASD, the Secretary of HHS should regularly engage key non-member federal agencies that serve or provide supports to young adults with autism in IACC activities. This could include, for example, directly engaging and soliciting input from federal agencies on

the IACC strategic plan, or inviting other federal agencies that serve or provide supports to young adults with autism to become IACC members.

To implement the goals and policy priorities of the 2020 Federal Youth Transition Plan, the Federal Partners in Transition (FPT) workgroup—the Secretaries of HHS, Education, DOL, and the Commissioner of SSA—should develop a long-term implementation plan that includes milestones and specific agency roles and assignments.

Agency Comments and Our Evaluation

We provided a draft of this report to the Departments of Education, Health and Human Services, Housing and Urban Development, Labor, and the Social Security Administration for review and comment. Education's written comments are reproduced in appendix III. DOL's written comments are reproduced in appendix IV. SSA's written comments are reproduced in appendix V. HUD did not provide formal comments on our report. HHS did not provide formal comments in time to be included in the final report, but indicated that it agreed with both recommendations directed to HHS. Education and HHS provided technical comments, which we incorporated in the report, as appropriate.

Regarding the two recommendations we made to Education, in its written comments, Education neither agreed nor disagreed with the first recommendation that it examine outcomes for transition services for students with disabilities that begin at age 16 and to examine the merits and implications of lowering the transition age. Rather, it noted that its Institute of Education Sciences has funded 29 research grants related to transition planning since 2006, representing an investment of about \$53 million to improve outcomes for students in transition. Education also stated that transition outcome data it currently collects are not disaggregated by the age at which children received transition services. We updated the report to provide additional detail on the research funded by Education. Education agreed with the second recommendation regarding the need for a long term implementation plan with milestones, roles, and responsibilities for the FPT. Finally, though our recommendation regarding the IACC was not directed to Education, it stated that, as an active member agency, it would be pleased to engage with additional federal agencies identified by HHS.

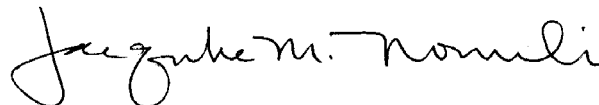
In its written comments, DOL stated that it agreed with our recommendation that the FPT should include a more comprehensive strategy describing precisely how its priorities will be carried out. DOL noted the FPT in 2017 has identified its annual policy priorities and will

continue to develop plans, identify milestones, and assign responsibility for joint activities and deliverables. In addition, DOL stated that it agreed that interagency collaboration will help the IACC fulfill its role in improving the well-being of individuals with ASD.

SSA, in its written comments, stated that, as a member of the FPT, it agreed to work toward accomplishing the goals laid out in the 2020 Federal Youth Transition Plan, but that the voluntary, ad hoc nature of the FPT precludes definitive implementation plans. However, we maintain being a voluntary initiative does not preclude the FPT from establishing long-term milestones and clarifying roles and responsibilities. As we stated in our report, we believe that without a long-term implementation plan that includes milestones and specific agency roles and assignments, it is less likely that the priorities outlined in the Federal Youth Transition Plan will be achieved. SSA also stated that HHS has extended an invitation for SSA to participate in an IACC meeting, and noted this will facilitate collaboration across federal agencies to improve the well-being of individuals with ASD.

We are sending copies of this report to the appropriate congressional committees, the Secretary of the Department of Education, the Secretary of the Department of Health and Human Services, the Secretary of the Department of Housing and Urban Development, the Secretary of the Department of Labor, and the Commissioner of the Social Security Administration, and other interested parties. In addition, the report is available at no charge on the GAO website at <http://www.gao.gov>.

If you or your staff have any questions about this report, please contact me at (617) 788-0580 or nowickij@gao.gov. Contact points for our Offices of Congressional Relations and Public Affairs may be found on the last page of this report. GAO staff who made key contributions to this report are listed in appendix viii.



Jacqueline M. Nowicki
Director, Education, Workforce and
Income Security

Appendix I: Objectives, Scope, and Methodology

In this report, we examined three objectives: (1) the types of services and supports provided at the local level to assist youth with Autism Spectrum Disorder (ASD) in transitioning to adult life, (2) the key challenges for youth with ASD in successfully transitioning to adult life, and (3) the extent to which key federal agencies have collaborated to assist youth with ASD in successfully transitioning to adult life. To address these objectives, we used a variety of methods, including a web-based survey of school districts;¹ interviews with representatives of state agencies and local service providers in selected states; discussion groups with family members of and youth with ASD; reviews of federal laws and regulations; and interviews with representatives of federal agencies, employers, and national disability advocacy organizations.

We conducted this performance audit from November 2015 through April 2017 in accordance with generally accepted government auditing standards. Those standards require that we plan and perform the audit to obtain sufficient, appropriate evidence to provide a reasonable basis for our findings and conclusions based on our audit objectives. We believe that the evidence obtained provides a reasonable basis for our findings and conclusions based on our audit objectives.

Web-based Survey of School Districts

To examine the types of services and supports provided at the local level to assist youth with ASD in transitioning to adult life and the key challenges for youth with ASD in successfully transitioning to adult life, we designed and administered a generalizable, stratified random sample of U.S. local educational agencies (LEA), which we refer to as school districts throughout the report, serving high school-aged students. The survey included questions about services and supports school districts provided to students aged 16 to 21 with ASD in special education during the 2015-16 school year to assist in their transition to adult life. We also

¹For the purposes of the survey, we used the term ASD to refer to students receiving special education services who are classified with autism for Individuals with Disabilities Education Act (IDEA) reporting purposes. For the purposes of reporting on students with disabilities under IDEA, the U.S. Department of Education defines autism as “a developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age 3, that adversely affects educational performance. Other characteristics often associated with autism are engagement in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences. Autism does not apply if a child’s educational performance is adversely affected primarily because the child has an emotional disturbance.”

asked questions about services provided,² the types of challenges in providing services, and the level of difficulty in providing services with regard to students with low-, moderate-, and high-intensity service needs.³ Further, we asked about the age at which transition services and supports are included in the students' individualized education programs (IEP) and the age it would be most beneficial to begin including these services in their IEPs. We also asked about perspectives on the factors that may negatively affect students once they exit school in obtaining services to assist with transitioning to adult life. We directed the survey to school districts' special education directors.

We defined our target population to be all currently operating LEAs offering at least one high school level grade (9, 10, 11, or 12) operating within the 50 U.S. states and the District of Columbia that are not under the jurisdiction of the Department of Defense (DOD) or Bureau of Indian Education (BIE). We used the LEA Universe database from the Department of Education's (Education) Common Core of Data (CCD) for the 2013-14 school year to build the sampling frame of 12,955 LEAs. We selected a stratified random sample of 606 LEAs. We stratified the sampling frame into 13 mutually exclusive strata based on LEA size, urban classification, and poverty classification. We further stratified the LEAs classified as being in a city by charter status. We selected the largest 100 LEAs with certainty and determined the minimum sample size needed to achieve precision levels of plus or minus 10 percentage points or fewer, at the 95 percent confidence level, for six sub-population estimates based on three urban classifications (city, suburban, and town/rural) and three classifications of poverty (high-, medium-, and low-poverty districts). We then increased the sample size within each stratum for an expected response rate of 70 percent.

²To develop the list of transition-related services used in the survey, we reviewed related reports on transition and gathered feedback from transition coordinators and special education directors in various school districts. We continued to ask school districts for feedback on the list throughout our survey development.

³In the survey, we used the following definitions of low-, moderate-, and high-intensity service needs, based on the U.S. Department of Education's environmental categories for IDEA reporting: We defined students with low-intensity service needs as those students who spend 80 percent or more of their day in the regular classroom; students with moderate-intensity service needs as those students who spend between 79 and 40 percent of their day in the regular classroom; and students with high-intensity service needs as those students who spend less than 40 percent of their day in the regular classroom. These terms are not found in IDEA or the Rehabilitation Act.

We defined the three urban classifications based on the National Center for Education Statistics (NCES) urban-centric locale code, ULOCAL. To build a general measure of the poverty level for each LEA, we used the proportion of students eligible for free or reduced price lunch (FRPL) and classified these into the following three groups:

- High-poverty: More than 75 percent of students in LEA were eligible for FRPL;
- Mid-poverty: Between 25.1 and 75.0 percent of students in LEA were eligible for FRPL; and
- Low-poverty: 25 percent or fewer students in LEA were eligible for FRPL.

We identified that 18 of the 606 sampled LEAs were either closed or did not serve high school-aged students. We received valid responses from 414 (70 percent) of the remaining 588 eligible sampled LEAs. The weighted response rate, which accounts for the differential sampling fractions within strata, is 71 percent. The survey was in the field from May to August 2016. To obtain the maximum number of responses to our survey, we sent reminder emails to nonrespondents and contacted nonrespondents over the telephone.

We conducted an analysis of our survey results to identify potential sources of nonresponse bias using two methods. First, we examined the response propensity of the sampled LEAs by several demographic characteristics. These characteristics included poverty, urbanicity and race. Our second methodology consisted of comparing weighted estimates from respondents and nonrespondents to known population values. The results of this nonresponse bias analysis showed no significant differences in response propensities or between known population values and estimates for nearly all of the characteristics we examined. Based on these results and the 71 percent weighted response rate, we determined that weighted estimates generated from these survey results are generalizable to the population of eligible LEAs and are sufficiently reliable for the purposes of this report.

We took steps to minimize non-sampling errors, including pretesting draft instruments and using a web-based administration system. During survey development, we met with officials from eight school districts to explore the feasibility of responding to the survey questions. We then pretested the draft instrument from March to April 2016 with officials in 11 school districts in a range of city, suburban, and rural districts. In the pretests, we

asked about the clarity of the questions and the flow and layout of the survey. Based on feedback from the pretests, we made revisions to the survey instrument. To further minimize non-sampling errors, we used a web-based survey, which allowed respondents to enter their responses directly into an electronic instrument. Using this method automatically created a record for each respondent in a data file and eliminated the errors associated with a manual data entry process.

Because we followed a probability procedure based on random selections, our sample is only one of a large number of samples that we might have drawn. Because each sample could have provided different estimates, we express our confidence in the precision of our particular sample's results as a 95 percent confidence interval (e.g., plus or minus 7 percentage points). This is the interval that would contain the actual population value for 95 percent of the samples we could have drawn. As a result, we are 95 percent confident that each of the confidence intervals in this report will include the true values in the study population. All percentage estimates presented in this report from this survey have a margin of error of plus or minus 11.8 percentage points or fewer, unless otherwise noted.

To analyze differences we identified in the percentages of LEAs providing services between size, socioeconomic, and urban factors, we compared weighted survey estimates generated for different levels of these subgroups and conducted multivariate logistic regression analyses to confirm statistical significance while controlling for other factors. We estimated models independently for each of the 17 services in the survey and controlled for poverty status, urbanicity, LEA size, charter school status, racial composition, and the interaction between school LEA size and urbanicity.⁴ To account for the stratified random sample design and the unequal probabilities of selection, we used SAS PROC SURVEYLOGISTIC and included the final sampling weights and strata boundaries. For each model, we produced parameter estimates and standard errors for each level of the factors we included in the model and

⁴We did not control for potential differences in the needs of students in school districts of different sizes, socioeconomics, or urbanicity.

used these results to confirm the significance of the differences between weighted survey estimates.⁵

Interviews with State Officials and Local Service Providers

To examine the types of services and supports provided at the local level to assist youth with ASD in transitioning to adult life and the key challenges for youth with ASD in successfully transitioning to adult life, we conducted interviews with stakeholders in selected states and local areas. We selected three states—Arizona, New Jersey, and South Carolina—to conduct interviews with local and state stakeholders.⁶ We selected these states because they include a variety of local areas with adult providers specifically involved with initiatives to serve individuals with autism and those that do not, as well as a mix of rural, suburban, and urban localities, and geographic dispersion.

In two states, Arizona and New Jersey, we conducted site visits and phone interviews with local and state entities. As part of these local interviews, in each of these states we conducted interviews with officials in two school districts and staff from at least one postsecondary education institution. We also met with public high school special education teachers and multiple adult service providers in each state. In each state, we focused our interviews on two local areas representing diversity in poverty status and urbanicity. In Arizona, our interviews focused on Phoenix and the rural areas around Flagstaff. In New Jersey, our interviews focused on the Princeton and Newark areas.

At the state level, we conducted interviews by phone with representatives of state special education, development disabilities, vocational rehabilitation, as well as behavioral health services agencies. We also interviewed representatives of university centers of excellence, parent training and information centers, the state developmental disabilities council, and state disability advocacy organizations.

To gather additional information on service provision after high school, we conducted phone interviews in a third state, South Carolina, with two

⁵We used a 90 percent confidence level as a measure of general significance. We chose this as the measure of significance because this analysis was designed to be a confirmatory analysis to provide additional evidence that the observed differences in the weighted estimates were not a result of other factors.

⁶For this report, unless otherwise noted, we use the term “stakeholders” to include parents and family members in our discussion groups, service providers, and/or advocacy group.

adult service providers and postsecondary institutions. We also conducted interviews with officials from the state vocational rehabilitation and disabilities agencies, as well as other state level disability organizations.

Information we gathered from these interviews represents only the conditions present in the states and local areas at the time of our interviews. These interviews focused on in-depth analysis of only a few selected states and local areas and therefore cannot be generalized nationwide. In addition, while we interviewed one health care provider in Arizona, we did not interview health care providers in all three states; thus, our findings related to medical services provided to transition-age youth with ASD are limited. However, we believe that these findings illustrate in-depth examples of services provided and perspectives on the challenges facing youth with ASD in transitioning to adult life.

Discussion Groups with Families and Youth with ASD

To describe services and challenges that youth with ASD face in transitioning to adult life, we held five discussion groups with family members of and youth with ASD in two states, Arizona and New Jersey. To organize these discussion groups, we identified organizations in the states that provide outreach services to youth with ASD and other disabilities to help us reach out to potential participants. We asked these organizations to distribute notices about the discussion groups to their members. We invited family members of and youth who had exited high school within the last 5 years. We selected this age range to ensure we gathered first-hand experiences of those who were or had recently transitioned to adult life. The number of family members and youth participating in each discussion group ranged from 7 to 15. The youth with ASD in attendance included high-, medium-, and low-need individuals.

We held all of the discussion groups in the evening to accommodate the schedules of families. We conducted discussion groups in New Jersey first, with two each in Newark and Princeton. However, after these initial discussion groups, we determined that one discussion group per local area was sufficient for our purposes. As a result, in Arizona we held one discussion group in the Phoenix area. We also scheduled a discussion group in the Flagstaff area to gather perspectives of individuals from the rural northern area of the state, but no individuals responded that they would attend. We tried other methods to reach families and youth with ASD in the rural areas of Arizona, but we did not receive responses from

individuals who met our criteria for participating (i.e., age and diagnosis of ASD).

Each discussion group was led by a trained facilitator using an interview protocol designed for family members and youth with ASD. Information and views obtained from these discussion groups are not generalizable to other families, family members, or youth with ASD.

Review of Federal Laws and Regulations, and Interviews with Federal Agency Officials

To examine the extent to which key federal agencies have collaborated in their efforts to assist youth with autism in successfully transitioning to adult life, we reviewed relevant federal laws, including the Autism Collaboration, Accountability, Research, Education, and Support Act of 2014 (Autism CARES Act); the Individuals with Disabilities Education Act; and the Rehabilitation Act of 1973, as amended by the Workforce Innovation and Opportunities Act in 2014; regulations; policy and guidance. We also interviewed officials from the Departments of Education (Education), Health and Human Services (HHS), Housing and Urban Development (HUD), and Labor (DOL); the Social Security Administration (SSA); the Interagency Autism Coordinating Committee (IACC); and the Federal Partners in Transition interagency workgroup, which is composed of Education, HHS, DOL and SSA. We evaluated their collaborative efforts against leading federal practices for interagency collaboration, as appropriate.⁷ Four of the federal agencies included in our review—Education, HHS, DOL, and SSA—are the key agencies we identified in our 2012 report that administer key programs serving transition-age youth with disabilities in their transition out of high school.⁸

⁷GAO, *Results-Oriented Government: Practices That Can Help Enhance and Sustain Collaboration among Federal Agencies*, [GAO-06-15](#) (Washington, D.C.: Oct. 21, 2005); and *Managing for Results: Key Considerations for Implementing Interagency Collaborative Mechanisms*, [GAO-12-1022](#) (Washington, D.C.: Sept. 27, 2012). We reviewed collaboration efforts of the Federal Partners in Transition against all of the leading practices for interagency collaboration. Because we have conducted recent reviews of collaboration related to the IACC, we selected the practices most relevant to the focus of our review. For those recent reports, see GAO, *Combating Autism Act: HHS Agencies Responded with New and Continuing Activities, Including Oversight*, [GAO-13-232](#) (Washington, D.C.: Feb. 27, 2013); GAO, *Federal Autism Activities: Better Data and More Coordination Needed to Help Avoid the Potential for Unnecessary Duplication*, [GAO-14-16](#) (Washington, D.C.: Nov. 20, 2013); and GAO, *Federal Autism Activities: Agencies Are Encouraging Early Identification and Providing Services, and Recent Actions Could Improve Coordination*, [GAO-16-446](#) (Washington, D.C.: May 20, 2016).

⁸GAO, *Students with Disabilities: Better Federal Coordination Could Lessen Challenges in the Transition from High School*, [GAO-12-594](#) (Washington, D.C.: July 12, 2012).

In addition, we also included HUD in our review based on federal agency feedback to that report and to consider any collaboration related to housing programs.

**Interviews with Employers
and National
Organizations**

To inform all of our research objectives, we interviewed representatives of three businesses that have initiatives to hire individuals with ASD or with disabilities in general. We also interviewed representatives from a broad range of national disability advocacy organizations including The Arc, the Autism Self Advocacy Network, Autism Speaks, Autism Science Foundation, Easter Seals, and the National Association of Councils on Developmental Disabilities.

Appendix II: Federal Agency Collaboration Has Highlighted Priority Research Needs

The Interagency Autism Coordinating Committee (IACC) and the Interagency Committee on Disability Research (ICDR) have identified priority areas in which more research is needed to help youth with Autism Spectrum Disorder (ASD), or youth with disabilities more broadly, transition to adult life.¹

- **IACC:** The IACC identified the need for additional research in areas related to transition-age youth and adults with ASD in multiple strategic plans, including its most recent strategic plan from 2013. In its 2013 plan, the IACC identified several areas related to transition-age youth and young adults that needed additional research, including understanding how ASD unfolds across the lifespan, development of treatments and interventions for individuals, developing specialized training for providers, and evaluating the effectiveness of service approaches.² The IACC expressed urgency for research on adult issues related to ASD, noting the lack of knowledge on effective approaches to service delivery. According to the 2013 IACC Portfolio Analysis of Federal and private autism research funding, the IACC Strategic Plan Question 6 topic area, which focuses on research related to quality of life for adults and transition-age adults with autism, including participation in the community and supports necessary for access to individualized services and supports, received roughly 1 percent of overall autism research funding, relatively little research funding compared to other Question areas that year.
- **ICDR:** The ICDR is tasked with promoting coordination and cooperation among federal departments and agencies conducting disability, independent living, and rehabilitation research programs.³ In

¹The Workforce Innovation and Opportunity Act (WIOA) advisory committee report is another example of a collaborative effort that has identified priority areas in which more focus is needed to help youth with disabilities, including youth with ASD, transition to adult life, but the report was not research focused. The Advisory Committee on Increasing Competitive Integrated Employment for Individuals with Disabilities Final Report (September 15, 2016).

²*The Interagency Autism Coordinating Committee: Strategic Plan For Autism Spectrum Disorder Research*, 2013 Update. (April 2014).

³The ICDR was established in 1978 in an amendment to the Rehabilitation Act of 1973, and was initially called the Interagency Committee on Handicapped Research within the Department of Health, Education, and Welfare. It was originally tasked with promoting coordination and cooperation among federal departments and agencies conducting rehabilitation programs related to handicapped individuals and producing an associated report annually. Rehabilitation, Comprehensive Services, and Developmental Disabilities Amendments of 1978, Pub. L. No. 95-602, § 109, 92 Stat. 2955, 2962-66.

2014, the Workforce Innovation and Opportunity Act (WIOA) included a requirement for the ICDR to develop a comprehensive government-wide strategic plan for disability, independent living, and rehabilitation research. The ICDR draft strategic plan contains four overall cross-cutting themes, one of which is transition, and the plan points to the need for methods to more efficiently advance research on transitions to education, employment, and community living.⁴ Additionally, one of the ICDR workgroups that assisted in creating the draft strategic plan highlighted additional research needs in the youth transition area, such as a focus on outcomes necessary to identify and share effective practices; and future research on the value of work experience and early VR involvement.

⁴The ICDR Draft Government Wide Strategic Plan was released in September 2016 and according to the draft plan, describes the planning process used to develop the Government Wide Strategic Plan for fiscal years 2017-2020, as well as the strategic goals and objectives the ICDR will pursue over the next 3 years.

Appendix III: Comments from the Department of Education



UNITED STATES DEPARTMENT OF EDUCATION
OFFICE OF SPECIAL EDUCATION AND REHABILITATIVE SERVICES

APR 6 2017

Ms. Jacqueline M. Nowicki
Director
Education, Workforce and Income Security
U.S. Government Accountability Office
441 G Street, NW
Washington, DC 20548

Dear Ms. Nowicki:

I am writing to respond to recommendations made in the Government Accountability Office (GAO) draft report, "Youth With Autism: Federal Agencies Should Take Additional Action To Support Transition-Age Youth," (GAO-17-352). The U.S. Department of Education (Department) appreciates the opportunity to respond to the draft report, which uses "autism spectrum disorder" (ASD) terminology to identify the condition. Below please find the Department's responses to the three recommendations to federal agencies that were included in this report.

Recommendation (1) To determine whether IDEA's current transition age requirement allows youth with disabilities, including those with ASD, the time needed to plan and prepare for the transition to adult life, the Secretary of Education should examine outcomes for students when transition services begin at age 16 and the merits and implications of amending IDEA to lower the age at which school districts are to begin providing transition services to students with disabilities, such as 14.

Response: We have several observations regarding this recommendation. The Department is neither making nor commenting upon any specific legislative recommendations for the Individuals with Disabilities Education Act (IDEA) at this time. The Department also notes that the transition outcome data currently collected by the Department is through two sources: (1) the State annual performance report (APR) Indicator 14 data under Part B of IDEA; and (2) the 2012 National Longitudinal Transition Study. Neither of these data sources collect data that are disaggregated by the age at which children received transition services, (i.e., age 14 as opposed to age 16) and they reflect the current IDEA statutory requirement that children receive transition services by age 16.

Nothing in IDEA precludes schools or local educational agencies from providing transition planning or transition services to children under age 16, and some states currently provide for such planning and services at a lesser age under state law. As GAO has observed, the most recent IDEA reauthorization raised the age specification for transition services, as a requirement, from age 14 to the present age 16.

In regard to the examination of outcomes, the Department, through the Institute of Education Sciences, has funded 29 research grants, representing an investment of about \$53 million to improve outcomes for students in transition, including postsecondary enrollment, employment opportunities, and community involvement after high school. Of note is a current \$10 million investment in developing and testing a comprehensive intervention (targeting academic performance; social

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The Department of Education's mission is to promote student achievement and preparation for global competitiveness by fostering educational excellence and ensuring equal access.

competence and peer relations; adaptive behavior; and transition and family) specifically for students with autism in high school. Please see: (<https://ies.ed.gov/funding/grantsearch/details.asp?ID=1334>). We provide additional background information in our technical comments about the examination of outcomes through research.

Recommendation (2) To improve collaboration and leverage the knowledge of key federal agencies serving youth with ASD, the Secretary of HHS should regularly engage key non-member federal agencies that serve or provide supports to young adults with autism in IACC activities. This could include, for example, directly engaging and soliciting input from federal agencies on the IACC strategic plan, or inviting other federal agencies that serve or provide supports to young adults with autism to become IACC members.

Response: The Department has been a statutory member of, and active participant in, the Interagency Autism Coordinating Council (IACC) since the inception of the body. The Department would be pleased to engage, as appropriate, with additional federal agencies that might be identified by the Secretary of Health and Human Services as having programmatic involvement with services to young adults with ASD.

Recommendation (3) To implement the goals and policy priorities of the 2020 Federal Youth Transition Plan, the Federal Partners in Transition (FTP) workgroup – the Secretaries of HHS, Education, DOL, and the Commissioner of SSA – should develop a long term implementation plan, including milestones and specific agency roles and assignments.

Response: We concur with the recommendation regarding the Federal Partners in Transition workgroup, in which the Department has been an active participant. Plans, roles and milestones involving Department programs will be developed with the approval of Departmental leadership and in cooperation with the other FTP partners.

We are providing you under separate cover the Department's technical comments on the draft report, for your consideration.

Again, the Department appreciates the opportunity to respond to the draft report. If you or your staff members have any questions regarding our response, please contact me at (202) 245-7459 or e-mail (Ruth.Ryder@ed.gov).

Sincerely,



Ruth E. Ryder
Delegated the duties of the Assistant
Secretary for Special Education and
Rehabilitative Services

Appendix IV: Comments from the Department of Labor

U.S. Department of Labor

Office of Disability Employment Policy
Washington, D.C. 20210



Ms. Jacqueline M. Nowicki
Director, Education, Workforce and Income Security
U.S. Government Accountability Office
441 G Street, NW
Washington, DC 20548

Dear Ms. Nowicki:

Thank you for providing the U.S. Department of Labor (DOL) with the opportunity to review and comment on the U.S. Government Accountability Office's (GAO) draft report entitled, "Youth with Autism: Federal Agencies Should Take Additional Action to Support Transition Age Youth." At DOL, we recognize that all students, and in particular students with disabilities, face challenges when navigating from secondary education into postsecondary education and employment. DOL remains committed to working collaboratively with our federal partners in the Departments of Education (ED) and Health and Human Services (HHS), and the Social Security Administration (SSA) to support the transition of youth with disabilities, including those with autism spectrum disorder (ASD). This is evidenced by the steps that DOL and the partner agencies that comprise the Federal Partners in Transition (FPT) interagency workgroup have taken to develop and implement, *The 2020 Federal Youth Transition Plan: A Federal Interagency Strategy (2020 Plan)*. Released in February 2015, the 2020 Plan is an interagency strategy to ensure that federal programs and resources are optimized to support our nation's youth and young adults with disabilities in reaching their goals of economic empowerment and independence. Since its development, the 2020 Plan has served as a blueprint for the FPT's efforts to improve the provision of transition services to students with disabilities through enhanced coordination among the multiple programs that support the population.

We agree with the report's recommendation that the FPT should include a more comprehensive strategy describing precisely how its priorities will be carried out. As GAO suggests, this would necessarily include timelines, milestones, and deadlines for specific actions that drive the priorities of the workgroup. The FPT Steering Committee, comprised of career and senior executive staff from ED, HHS, DOL and SSA, meets quarterly to identify both short and long term goals for the FPT. The jointly developed policies of the steering committee will ensure each agency understands its roles and responsibilities, that resources are fully leveraged, and that agencies can be held accountable for this work going forward. In 2017, the FPT has already identified its annual policy priorities and will continue to develop plans and indicators approved by and consistent with the goals identified by the incoming Administration and will assign agencies responsibility for joint activities and deliverables.



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Page 2

With reference to the Interagency Autism Coordinating Committee (IACC), the DOL agrees that interagency collaboration will help the IACC to fulfill its role in improving the well-being of individuals with ASD. In 2016, DOL participated in a workgroup convened by the National Autism Coordinator to provide input into a report mandated by the Autism CARES Act of 2014. DOL continues to actively participate in this workgroup and will seek additional opportunities to work with the IACC on employment and transition-related issues.

Again, thank you for the opportunity to review and comment on the draft report.

Sincerely,



Jennifer C. Sheehy
Deputy Assistant Secretary

Appendix V: Comments from the Social Security Administration



SOCIAL SECURITY
Office of the Commissioner

April 10, 2017

Ms. Barbara D. Bovbjerg
Managing Director
Education, Workforce and Income Security Issues
United States Government Accountability Office
441 G. Street, NW
Washington, DC 20548

Dear Ms. Bovbjerg,

Thank you for the opportunity to review the draft report, "YOUTH WITH AUTISM: Federal Agencies Should Take Additional Action To Support Transition-Age Youth" (GAO-17-352). Please see our enclosed comments.

If you have any questions, please contact Gary S. Hatcher, Senior Advisor for the Audit Liaison Staff, at (410) 965-0680.

Sincerely,


Stephanie Hall
Acting Deputy Chief of Staff

Enclosure

SOCIAL SECURITY ADMINISTRATION BALTIMORE, MD 21235-0001

COMMENTS ON THE GOVERNMENT ACCOUNTABILITY OFFICE DRAFT REPORT, "YOUTH WITH AUTISM: FEDERAL AGENCIES SHOULD TAKE ADDITIONAL ACTION TO SUPPORT TRANSITION-AGE YOUTH" (100433)

Thank you for the opportunity to review the draft report. We appreciate GAO's acknowledgement of our efforts to assist transition-aged youth with disabilities by providing cash benefits through the Disability Insurance and Supplemental Security Income programs. As a member of the Federal Partners in Transition Workgroup (FPT), formed in 2005 with our colleagues at the Departments of Labor, Education, and Health and Human Services (HHS), we strive to improve interagency policy and service coordination to support youth with disabilities, in successfully transitioning from school to adulthood. To support our efforts, the FPT developed the 2020 Federal Youth Transition Plan, which is a blueprint of our efforts to improve the provision of transition services to students with disabilities.

In addition, HHS has extended an invitation for us to participate in an Interagency Autism Coordinating Committee meeting. Our participation will further facilitate collaboration across Federal agencies to improve the well-being of individuals with Autism Spectrum Disorder.

Recommendation

To implement the goals and policy priorities of the 2020 Federal Youth Transition Plan, the Federal Partners in Transition (FPT) workgroup should develop a long-term implementation plan, including milestones and specific agency roles and assignments.

Response

We agree, as a key partner in the FPT workgroup, to work toward accomplishing the goals laid out in the 2020 Federal Youth Transition Plan that are within our purview and authority. However, the voluntary, ad hoc nature of the FPT endeavor precludes definitive implementation plans.

Appendix VI: GAO Contact and Staff Acknowledgments

GAO Contact

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Staff Acknowledgments

In addition to the contact named above, Scott Spicer (Assistant Director), Cady Panetta (Analyst-in-Charge), James Ashley, James Bennett, Holly Dye, Maria Gaona, Farrah Graham, Aaron Karty, Jamila Kennedy, Sheila McCoy, Walter Vance, Najeema Washington, Adam Wendel, and Khristi Wilkins made key contributions to this report.

Related GAO Products

Youth with Autism: Roundtable Views of Services Needed During the Transition into Adulthood. [GAO-17-109](#). Washington D.C.: October 18, 2016.

Federal Autism Activities: Agencies are Encouraging Early Identification and Providing Services, and Recent Actions Could Improve Coordination. [GAO-16-446](#). Washington D.C.: May 20, 2016.

Federal Autism Research: Updated Information on Funding from Fiscal Years 2008 through 2012. [GAO-15-583R](#). Washington, D.C.: June 30, 2015.

Federal Autism Activities: Funding and Coordination Efforts. [GAO-14-613T](#). Washington, D.C.: May 20, 2014.

Federal Autism Activities: Better Data and More Coordination Needed to Help Avoid the Potential for Unnecessary Duplication. [GAO-14-16](#). Washington, D.C.: November 20, 2013.

Combating Autism Act: HHS Agencies Responded with New and Continuing Activities, Including Oversight. [GAO-13-232](#). Washington, D.C.: February 27, 2013.

Students with Disabilities: Better Federal Coordination Could Lessen Challenges in the Transition from High School. [GAO-12-594](#). Washington D.C.: July 12, 2012.

Federal Autism Activities: Funding for Research Has Increased, but Agencies Need to Resolve Surveillance Challenges. [GAO-06-700](#). Washington, D.C.: July 19, 2006.

Special Education: Children with Autism. [GAO-05-220](#). Washington, D.C.: January 14, 2005.

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