



October 2016

YOUTH WITH AUTISM

Roundtable Views of Services Needed During the Transition into Adulthood

GAO Highlights

Highlights of [GAO-17-109](#), a report to congressional requesters

Why GAO Did This Study

About a half a million youth with ASD will enter adulthood over the next decade. As they exit high school, they must obtain services as adults. Previous GAO work has shown that students with disabilities who are transitioning to adulthood face challenges identifying and obtaining adult services. GAO was asked to study the services and supports youth with ASD need during the transition to adulthood. This is the first in a series of reports.

GAO studied (1) the services and supports transitioning youth with ASD need to attain their goals for adulthood, (2) the characteristics of these services and supports, and (3) how youth with ASD can be fully integrated into society. To address these objectives, GAO convened a roundtable discussion on March 3 and 4, 2016. GAO selected 24 panelists, including adults with ASD, service providers, researchers, and parents of youth with ASD. GAO interviewed prospective panelists in advance of the discussion and selected a panel with a broad base of expertise reflecting the diversity of the autism community.

The panel described the services and supports that youth with ASD may need to help them achieve five goals for adulthood: postsecondary education; employment; maximizing independent living; health and safety; and maximizing community integration. GAO analyzed the transcripts of the panel as well as documents provided by panelists. GAO is not making recommendations in this report.

View [GAO-17-109](#). For more information, contact Jacqueline M. Nowicki at (617) 788-0580 or nowickij@gao.gov.

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YOUTH WITH AUTISM

Roundtable Views of Services Needed During the Transition into Adulthood

What GAO Found

Youth with Autism Spectrum Disorder (ASD) transitioning to adulthood may need a wide range of services and supports to help them achieve their goals, according to a panel GAO convened in March 2016. ASD is a highly individualized condition with characteristics that vary in degree and type from person to person. Autism characteristics may hinder or help youth achieve their goals—such as postsecondary education and community integration. For each goal, the panel described services and supports that youth (ages 14-24) with ASD transitioning to adulthood may need to address autism characteristics and other health conditions that affect their ability to attain the goal. GAO grouped these services into 14 broad categories.

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 analysis of roundtable discussion. | [GAO-17-109](#)

To support a successful transition into adulthood, the panel said youth need to be able to access services that are individualized, timely, equitable, and community- and evidence-based, among other things. The panel discussed the need for timely, individualized services that address the variation in autism characteristics and any changes over a person's lifetime. For example, a person's verbal abilities may change over time, and their needs for communication services would also change. The panel said transitioning youth with ASD need equitable access to services regardless of their race, gender, family income, or location. For instance, the panel said that female and minority youth may be diagnosed at a later age and thus receive fewer services during school and may need additional transition planning services. The panel also emphasized the need for services within youths' local communities in order to foster access and community involvement. In addition, the panel said that while services should be evidence-based, more research into program efficacy is needed.

To improve the ability of autistic youth to fully integrate into society, the panel cited the need for a new approach to providing supports and better public understanding of autism. Such an approach would place a shared responsibility for inclusion on both society and youth with ASD. For example, according to the panel, youth with ASD should learn workplace social expectations and meet them to the extent they can, but employers should also recognize that some social rules, such as expecting individuals to smile, can be difficult for some individuals with autism. The panel also said that widespread knowledge of autism could lead to better understanding of autistic youths' potential and enhance their chances of attaining it.

Contents

Letter		1
	Background	4
	Panel Theme: Needs for Services and Supports Depend on Transitioning Youths' Goals for Adulthood	9
	Panel Theme: The Need for Access to Evidence-Based Services that Are Individualized, Flexible, Timely, and Provided in the Community	17
	Panel Theme: A New Approach to Supporting Youth with Autism to Enhance Their Integration into Society	24
	Agency Comments	28
Appendix I	Objectives, Scope, and Methodology	29
Appendix II	Agenda and List of Invited Panelists	33
Appendix III	Services and Supports for Transitioning Youth with Autism Identified By the Panel	37
Appendix IV	GAO Contact and Staff Acknowledgements	46
Tables		
	Table 1: Services Panelists Identified as Supporting Postsecondary Education Goals of Transitioning Youth with Autism Spectrum Disorders	11
	Table 2: Services Panelists Identified as Supporting Employment Goals of Transitioning Youth with Autism Spectrum Disorders	13
	Table 3: Services Panelists Identified as Supporting Independent Living Goals of Transitioning Youth with Autism Spectrum Disorders	14
	Table 4: Services Panelists Identified as Supporting Health and Safety Goals of Transitioning Youth with Autism Spectrum Disorders	16

Table 5: Services Panelists Identified as Supporting Community Integration Goals of Transitioning Youth with Autism Spectrum Disorders	17
Table 6: Services that Support five Goals that Youth with Autism Spectrum Disorders (ASD) May Pursue in Adulthood, According to the Panel	37

Figures

Figure 1: Autism Spectrum Disorder (ASD) Characteristics	5
Figure 2: Variation in Autism Spectrum Disorder Characteristics	6
Figure 3: Roundtable Views of Goals Supported by Behavioral Services	38
Figure 4: Roundtable Views of Goals Supported by Case management/Coordination	38
Figure 5: Roundtable Views of Goals Supported by Communication Services	39
Figure 6: Roundtable Views of Goals Supported by Day Programming	39
Figure 7: Roundtable Views of Goals Supported by Family Education and Supports	40
Figure 8: Roundtable Views of Goals Supported by Life Skills Education and Experience	40
Figure 9: Roundtable Views of Goals Supported by Medical Care Services	41
Figure 10: Roundtable Views of Goals Supported by Mental Health Care Services	42
Figure 11: Roundtable Views of Goals Supported by Postsecondary Education Supports	42
Figure 12: Roundtable Views of Goals Supported by Residential Supports	43
Figure 13: Roundtable Views of Goals Supported by Social Supports	43
Figure 14: Roundtable Views of Goals Supported by Transition Planning Services	44
Figure 15: Roundtable Views of Goals Supported by Transportation Supports	44
Figure 16: Roundtable Views of Goals Supported by Vocational Supports	45

Abbreviations

ADA	American with Disabilities Act of 1990
ASD	Autism Spectrum Disorder
Education	U.S. Department of Education
HHS	U.S. Department of Health and Human Services
IDEA	Individuals with Disabilities Education Act
IEP	Individualized Education Program
NLTS2	National Longitudinal Transition Study-2

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October 18, 2016

The Honorable Fred Upton
Chairman
Committee on Energy and Commerce
House of Representatives

The Honorable Joseph R. Pitts
Chairman
Subcommittee on Health
Committee on Energy and Commerce
House of Representatives

The Honorable Christopher H. Smith
House of Representatives

About a half million youth with Autism Spectrum Disorder (ASD) will enter adulthood over the next decade, according to a 2015 report.¹ As these students exit high school, they leave their school-based support systems behind and must obtain services as adults, making the transition to adulthood particularly challenging.² Commonly known as autism, ASD is a group of complex developmental disorders characterized by difficulties with social interactions and communication, highly focused interests, and repetitive or ritualized behaviors.³ While in elementary and secondary school, children with autism may receive many services—such as speech, behavioral, or occupational therapy, job training, and transportation—through their public schools, as required by the

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

² For convenience, we use the term “youth” in this report to describe individuals aged 14 to 24, the age range when they may be eligible for transition services, depending on their state. During the transition years, youth may receive services for children, adults, or both.

³ In this report, we use the following terms interchangeably: “individuals/youth with autism”, “individuals/youth with ASD”, and “autistic individuals.” Several panelists used the term “autistic” when describing themselves.

Individuals with Disabilities Education Act (IDEA).⁴ However, according to our prior work, these services typically end when youth exit from school. Once students with disabilities complete their high school program, many of them face significant challenges obtaining the services they need to make a successful transition to higher education, work, or community life.⁵

You asked us to provide information on the transition needs of youth with ASD. This report examines three questions:

1. What services and supports do transitioning youth with autism need to attain their goals for adulthood?
2. What are the characteristics of needed services and supports?
3. How can youth with autism be fully integrated into society?

This is the first in a series of reports on youth with autism who are transitioning to adulthood. In this report, we focus on describing the services that youth with ASD need to help them make a successful transition into adulthood. A second engagement will examine the services provided to transitioning youth with ASD and any challenges they may face obtaining them.

To answer our research questions, we convened a roundtable discussion on March 3 and 4, 2016. We selected a total of 24 panelists, including autistic adults, service providers, employers, researchers, and parents of youth with autism.⁶ We selected panelists based on their experience with or knowledge about autism, recommendations from other stakeholders with subject matter knowledge, and to ensure a variety of backgrounds and perspectives that reflect the diversity of the autism community, including variations in service areas, income, race, gender, geographic location, and urbanicity. See appendix I for our scope and methodology,

⁴ 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).

⁵ GAO, *Students with Disabilities: Better Federal Coordination Could Lessen Challenges in the Transition from High School*, [GAO-12-594](#) (Washington, D.C.: July 12, 2012).

⁶ Of the 24 invited panelists, 2 were not present at the meeting, including an autistic individual who does not use spoken language. We interviewed them afterward on the same topics covered during the panel and included this information in our analysis.

including more details about how we selected our panelists, and appendix II for a copy of the agenda for the event. We asked the panel about the services that transitioning youth across the autism spectrum need to help them achieve five goals for adulthood:

1. Postsecondary education.
2. Employment.
3. Maximizing independent living.
4. Health and safety.
5. Maximizing community integration.

We chose these goals because they were either listed in the transition planning requirements for high school students receiving special education services (goals 1, 2, and 3) or described by potential panelists in pre-selection interviews as particularly important (goals 4 and 5).⁷

We asked the panel to describe services ideally needed for a successful transition to adulthood, regardless of what services may currently be available or feasible. We did not verify the accuracy of the information they provided. The panel also pointed out that many of the services needed to support youth with ASD may also support youth with other disabilities. While we focus on how these services would particularly address characteristics associated with autism, the panel also cautioned against singling out autistic youth unnecessarily.

We identified the emerging themes which form the body of this report by conducting a content analysis of the transcript of the 2-day event as well as documents the panelists submitted to clarify or support information

⁷ See the background section for more information about special education and transition planning requirements.

discussed during the panel meeting.⁸ Our systematic content analysis allowed us to attribute these themes, as well as specific examples given for illustrative purposes, to “the panel” throughout this report. We asked panelists for comments on a draft of this report, which we incorporated as appropriate.

For the purpose of this report, when discussing services that transitioning youth with autism may need, we grouped services under 14 broad categories, such as life skills education and experience, family education and supports, and vocational supports. The actual range of services provided under these terms could be quite broad, with significant variation in method, purpose, philosophy, and effectiveness. See appendix III for details on these service categories.

We conducted this performance audit from July 2015 to October 2016 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.

Background

According to the Centers for Disease Control and Prevention, about 1 in 68 children were identified as having ASD in 2012 (about 1.5 percent of 8-year olds).⁹ ASD is a complex developmental disorder with characteristics that can range from mild to more pronounced (see fig. 1).

⁸ We used the NVivo content analysis software to categorize each sentence according to the goals, services, and/or cross-cutting needs being discussed. We identified the categories of services and cross-cutting needs—issues that applied to several services or goals, such as the need for sufficient access to supports or service provider accountability—by creating lists of each service and issue mentioned at least once during the discussion or documents. We then grouped services into 14 broad categories and cross-cutting needs into 13 broad categories based on their relatedness and our understanding of autism services garnered from literature and interviews. We analyzed the text in each category to identify emerging themes.

⁹ The Autism and Developmental Disabilities Monitoring Network is a group of programs funded by the Centers for Disease Control and Prevention 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 1: Autism Spectrum Disorder (ASD) Characteristics

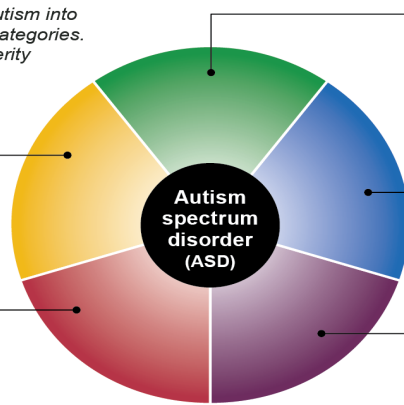
GAO grouped the characteristics associated with autism into five broad categories, with some overlap between categories. Autism is highly individualized, so the type and severity of characteristics experienced varies from person to person.

Social impediments

Social impediments may range from difficulties discussing emotions, making friends, or sharing interests to a complete disinterest in other people.

Communication difficulties

Difficulties with verbal and/or nonverbal communication may limit the ability to speak, understand and use gestures, or carry on a conversation.



Intense Focus/Interests

Individuals with ASD may have intense and specific interests, sometimes to the exclusion of other tasks or needs.

Sensitivities

Individuals with ASD may have unusually high or low sensitivities to environmental factors, such as certain sounds, lights, temperatures, or physical sensations.

Routine and repetition

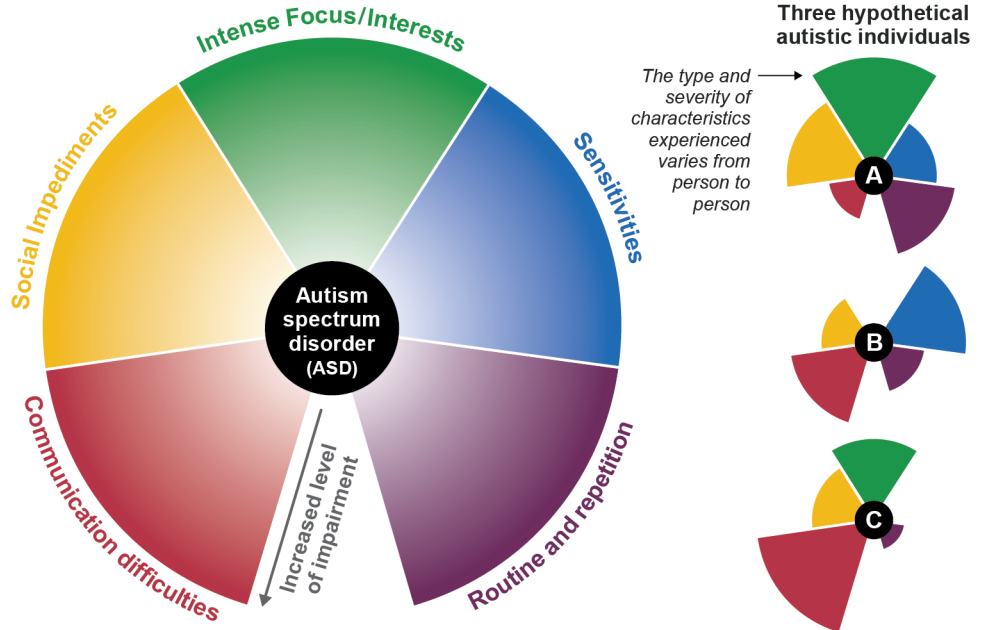
Individuals with autism may prefer sameness and strictly follow routines or ritualized patterns. They may have difficulty coping with changes or transitions.

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

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.

Figure 2: Variation in Autism Spectrum Disorder Characteristics

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



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

Other Health Conditions Often Associated with Autism

Certain medical or mental health conditions—called comorbid conditions—often occur with autism. For example, data from the 2011 Survey of Pathways to Diagnosis and Services showed that over half of autistic youth aged 15-17 had also been diagnosed with an attention deficit disorder (53 percent) or anxiety (51 percent), nearly one quarter had depression, and 60 percent had at least two comorbid conditions.¹⁰ Other common comorbid conditions include sleep disorders, intellectual disability, seizure disorders, and gastrointestinal ailments.

¹⁰ The Survey of Pathways to Diagnosis and Services studied children 6-17 years old who had special health care needs, including youth with autism. The data reported here were collected from the parents of autistic youth aged 15 to 17 who were receiving special education services. These data were reported by Roux et al.

Federally Required Education and Transition Services for Children and Youth with Disabilities

To support the educational needs of children with disabilities, Congress originally passed IDEA in 1975.¹¹ IDEA requires states and local educational agencies to identify and evaluate children with disabilities and provide special education and related services to those who are eligible. Such services and supports are formulated in an Individualized Education Program (IEP)¹² and may include speech or occupational therapy and behavioral supports, among others. The 2004 reauthorization of IDEA¹³ required that, beginning no later than age 16, a student's IEP must include measurable postsecondary goals, based on age-appropriate transition assessments, related to training, education, employment, and, where appropriate, independent living skills.¹⁴ The IEP must specify the transition services needed to assist the student in reaching those goals.¹⁵

Not all youth with autism received timely transition planning services, according to an analysis of data from the Department of Education's (Education's) National Longitudinal Transition Study-2 (NLTS2).¹⁶ That analysis showed that in 2009, 58 percent of young adults with ASD

¹¹ IDEA was originally enacted as the Education for All Handicapped Children Act of 1975, Pub. L. No. 94-142, 89 Stat. 773 (codified as amended at 20 U.S.C. §§ 1400-1482).

¹² 20 U.S.C. § 1414(d)(1)(A)(i)(IV).

¹³ 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). See 20 U.S.C. § 1414(d)(1)(A)(i)(VIII). Since 1990, IDEA has required transition services to be part of a student's IEP with refinements in subsequent reauthorizations.

¹⁴ Students 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 age range for which the state makes a free and appropriate public education available. While federal law authorizes students to receive a free appropriate public education until age 22, eligibility for students aged 18 to 21 is determined by states. Additionally, state laws may provide for high school attendance beyond age 22. 20 U.S.C. § 1412(a)(1); 34 C.F.R. § 300.102(a)(1).

¹⁵ Transition services may 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. See 20 U.S.C. § 1401(34).

¹⁶ Roux 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 at the final data collection in 2009. While Education planned another longitudinal study, no data were available at the time of this report.

reported that they had been given a transition plan by the federally required age. This percentage was lower for youth from lower income households, African-American youth, and youth with the highest conversation skills.¹⁷

Adult Service Delivery System

Upon exiting high school, youth with autism may obtain services by applying as adults and establishing eligibility for a number of programs. Specifically, we reported in 2012 that four federal agencies—Education, the Department of Health and Human Services (HHS), the Department of Labor, and the Social Security Administration—administer the key federal programs that provide services to youth with disabilities as they transition from high school. In addition, these and other federal agencies fund a number of other programs through grants to states, localities, and nongovernmental organizations, which often have flexibility on how to administer services. For example, Education’s Rehabilitation Services Administration funds state vocational rehabilitation agencies through formula grants, which have a state matching requirement, to help people with disabilities prepare for and engage in gainful employment,¹⁸ and some states use Medicaid funds to provide home and community-based services for individuals with certain types of disabilities who might otherwise be cared for in an institutional setting.¹⁹

In our 2012 report, we found that youth and their families faced challenges in identifying, navigating, and establishing eligibility for services for adults with disabilities, including autism.²⁰ In addition, we

¹⁷ Roux et al. The report found that less than half of youth with autism from low-income households had received transition planning services in a timely fashion, compared to 60 percent of youth with autism whose household incomes were above \$75,000. Also, 63 percent of youth with the lowest conversation skills and 48 percent of those with the highest skills had received timely transition planning.

¹⁸ 29 U.S.C. §§ 702, 706 and 721(a)(1)-(3).

¹⁹ States must obtain a waiver from Medicaid to provide home- and community-based care. Services provided with these waivers are individualized and may include case management, personal care attendants, or day or residential habilitation. Habilitation services are defined as “services designed to assist individuals in acquiring, retaining, and improving self-help, socialization, and adaptive skills necessary to reside successfully in home and community-based settings.” 42 U.S.C. § 1396n(c)(5). [GAO-12-594](#).

²⁰ [GAO-12-594](#).

found that the adult service system did not routinely provide a coordinated plan of services or objectives for youth making the transition to adulthood and—unlike the special education system for younger children—did less to ensure that needed services would be provided.²¹ Youth with autism who are entering the adult service system may have to apply to multiple agencies for services and establish their eligibility for each agency’s services. The difficulty obtaining adult services has been called “falling off a cliff” by the autism community.²²

Panel Theme: Needs for Services and Supports Depend on Transitioning Youths’ Goals for Adulthood

The panel told us that youth with ASD may need services addressing individual autism characteristics—or a combination of autism characteristics and other health conditions—that affect their ability to attain their goals for adulthood. The services needed to address any specific characteristic may differ depending on the goal. The panel told us that some characteristics of autism can be strengths that may help individuals with ASD achieve their goals—for example, intense focus on a specific interest can be very productive in the workplace. The panel discussed the importance of valuing the characteristics that may facilitate goals and warned against assuming that autism characteristics need to be “fixed.” The panel discussion, however, focused primarily on services and supports needed to address autism characteristics that can hinder progress toward goal attainment.

Goal: Postsecondary Education

The panel told us that, like their peers without autism, many youth with ASD pursue postsecondary education or training, although not all of them finish their academic programs. According to NLTS2, in 2009, 36 percent of young adults with ASD had attended some type of postsecondary education institution. Of those youth, 32 percent had attended a 4-year college, 70 percent had attended a 2-year college, and 33 percent had

²¹ As we recommended in our 2012 report, Education, HHS, the Department of Labor, and the Social Security Administration announced a strategy to enhance interagency coordination. The strategy features development of a shared vision, compatible outcome goals, and policy priorities that aim ultimately to lead to improved outcomes for youth with disabilities by 2020. See The 2020 Federal Youth Transition Plan: A Federal Interagency Strategy, prepared by the Federal Partners in Transition Workgroup, February 2015.

²² Roux et al.

attended a vocational, business, or technical school.²³ According to the panel, in addition to more traditional classroom settings, some youth with ASD also attend online programs and an increasing number of specialized colleges designed to meet the specific needs of students with disabilities.

According to the panel, youth with autism may need some of the same supports as other postsecondary students to help them succeed in the higher education environment, but may require increased intensity or providers with training in autism. For example, many students need help with organizational skills, such as managing time or prioritizing tasks, to keep up with the pace of academic demands. The panel cited mental health conditions, especially anxiety, as some of the biggest impediments to success in postsecondary education and said these conditions can have a greater effect than youths' autism characteristics. Youth may also need supports to help them navigate social demands of college life, such as relationships with roommates, dating, and issues with alcohol and drug use. The panel noted that self-care is especially important because poor personal hygiene can lead to isolation. The panel also discussed the need to have stronger supports at the beginning of college that taper down as students experience success and learn to navigate the environment. Table 1 shows some of the services and supports that may be needed in a postsecondary education environment.

²³ These percentages sum to greater than 100% 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 Schwarting, 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: Sept. 2001).

Table 1: Services Panelists Identified as Supporting Postsecondary Education Goals of Transitioning Youth with Autism Spectrum Disorders

	Selected aspects of the goal	
	Succeeding in academics	Handling social demands and living on campus
Services and supports that may address the needs	Organization and time management coaching ^a	Social supports, including mentoring, peer support, coaching, and training
	Autism assessments to help qualify for campus-based supports ^b	Training or coaching on daily living skills, such as laundry, cooking, and self care ^a
		Sexual education and health care ^b
	Self-advocacy coaching or training ^a	
Mental health care		

Source: GAO analysis of roundtable discussion. | GAO-17-109

^aFor the purposes of this report, we have classified these supports under “life skills training and experience.”

^bFor the purposes of this report, we have classified these supports under “medical care.”

Goal: Employment

Young adults with ASD have lower rates of employment than some other people with disabilities. For example, in 2009, 58 percent of youth with autism in their early 20s had ever worked for pay outside the home, compared to 91 percent of youth with emotional disturbances and 74 percent of youth with intellectual disabilities.²⁴ The diverse nature of autism means no single workplace setting or set of supports is appropriate for all autistic individuals. Examples of various workplace settings include the following:

- Full-time or part-time employment with market wages and responsibilities, with or without long-term supports—such as a job coach to help with communication and social navigation;
- Self-employment, which may offer the flexibility to tailor the job to the individual’s strengths and the work environment to their needs; and
- A workplace that primarily or exclusively employs individuals with disabilities—with wages that can fall below the federal minimum

²⁴ Roux et al.

wage.²⁵ Some workplaces provide services, supervision, or training in life skills or vocational skills.

Customized employment may provide an opportunity for some individuals with autism who might otherwise not be able to find employment. Employers create a job specifically designed for an individual's strengths, abilities and support needs.

The panel told us that the type and level of supports that youth may need to succeed in the workplace may vary over time. For example, youth may need training in job-seeking, interviewing, or organizational skills at the beginning of their employment, while they may need job coaching throughout their employment. The panel noted that while some programs may teach youth with autism how to interview and some of the logistics of work, youth also need to learn about navigating the social aspect of employment and may require ongoing support in this area. The panel noted that social difficulties in the workplace could lead to isolation, marginalization, or job termination. Additionally, according to the panel, some vocational supports could help youth find jobs that build on some of their autism strengths, such as the ability to focus intensely on a problem or activity or skills in following routines and performing tasks consistently. Some of the services and supports the panel discussed in conjunction with successful employment are highlighted in table 2.

²⁵An employer may obtain authority to pay wages lower than the otherwise applicable minimum wage to workers whose productivity is impaired by age, physical or mental deficiency, or injury. 29 U.S.C. § 214(c)(1); 29 C.F.R. pt. 525.

Table 2: Services Panelists Identified as Supporting Employment Goals of Transitioning Youth with Autism Spectrum Disorders

	Selected aspects of the goal		
	Finding the right job; building on strengths	Accomplishing daily work tasks	Handling the work environment
Services and supports that may address the needs	Vocational/career assessments; vocational/career training; assistance with job searches or interviewing skills; facilitating communication with employers ^a	Organization and time management training or coaching ^b	Social skills coaching, mentoring, peer support ^c
	Assessments of autism characteristics and needs ^d	Transportation supports	Personal hygiene coaching or aids ^b
		Job coaching, job aids ^a	
	Employer supports, including information about hiring and working with autistic employees ^a	Workplace adaptations to address sensory issues, such as non-flourescent lighting, sound protection, and privacy	
		Self-advocacy coaching or training ^b	

Source: GAO analysis of roundtable discussion. | GAO-17-109.

^aFor the purposes of this report, we have classified these supports under “vocational supports.”

^bFor the purposes of this report, we have classified this support under “life skills training and experience.”

^cFor the purposes of this report, we have classified this support under “social supports.”

^dFor the purposes of this report, we have classified this support under “medical care.”

Goal: Maximizing Independent Living

One of the goals of IDEA is to prepare students for independent living.²⁶ The level of independence that autistic youth may achieve varies widely—some are able to live in their own home (with or without supports), while others require 24-hour care. According to an analysis of NLTS2, young adults with autism are less likely to live independently than youth with other disabilities, including intellectual disabilities and emotional disturbances.²⁷ Specifically, in 2009, 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

²⁶ One 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).

²⁷ The 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.

group home or medical facility, which may have provided services such as life skills education or vocational supports.²⁸

The panel discussed two key aspects of independence—performing daily living activities and making and carrying out decisions. Daily living activities may include tasks such as cleaning, shopping, paying bills, maintaining personal hygiene, and preparing meals. Again, while some youth with ASD do not need help with these activities, some may need to learn these skills step by step and then practice them in real life to gain proficiency. For example, some youth may need a list of each step of washing hair—shampoo in hand, lather into hair, rinse, etc. The panel said that some youth may be able to perform tasks in isolation, but may have trouble combining them with employment or social demands. Youths’ abilities to make their own decisions may also vary, depending on their skills in communication and self-advocacy—identifying and expressing their needs to others. Regardless of their level of disability, the panel said that it is critically important that all youth be given the opportunities to state their own preferences to the extent of their capabilities. Table 3 shows some of the services and supports that the panel said may help youth reach their maximum independence.

Table 3: Services Panelists Identified as Supporting Independent Living Goals of Transitioning Youth with Autism Spectrum Disorders

	Selected aspects of the goal	
	Performing tasks of daily life	Making own decisions
Services and supports that may address the needs	Training, coaching, and practicing activities of daily life ^a	Communication aids
	Organization and time management aids or coaching ^a	Formal or informal assistance with medical, legal, financial, or privacy decisions ^b
	Transportation supports	
	Housing models that include appropriate supports	
	Mental health care	
	Self-advocacy coaching or training ^a	

Source: GAO analysis of roundtable discussion. | GAO-17-109

²⁸ Roux et al.

^aFor the purposes of this report, we have classified these supports under “life skills training and experience.”

^bFor the purposes of this report, we have classified this support under “family education and supports.”

Goal: Health and Safety

Health and safety are essential to maintaining a quality life for all people, including youth with ASD. According to the panel, health and safety are the primary goals for some youth with high support needs. The panel said that in order for youth with ASD to achieve health and safety, there need to be enough medical and mental health caregivers who are trained in the unique needs of patients with ASD and prepared to accommodate them. The panel noted that physical or mental comorbid conditions are sometimes more of a concern than autism. For example, unaddressed mental health issues like depression or anxiety can lead to lower social and life skills and increased self-injurious behavior, family stress, and suicidal thoughts and behaviors. The panel also discussed sleep issues—such as difficulty going to sleep or remaining asleep—and noted that youth with ASD can have sleep disruptions lasting several days. Extended sleep deprivation could have severe effects on a person’s ability to function and manage their autism characteristics. Finally, the panel said that reproductive and sexual health care were often overlooked due to mistaken assumptions that autistic youth would not engage in sexual relationships.

In addition, the panel discussed several reasons that youth with ASD may need supports to help them maintain their safety. For example, the panel told us that youth with ASD are more likely to be bullied or abused than other youth; some youth with ASD experience aggressive or self-injurious behavior, especially when they are frustrated or in pain; and some autistic youth wander away from their caregivers and are hit by cars or drown. The panel also discussed how some of the social and communication difficulties of ASD can make it hard for youth to tell when a situation or person is dangerous, and gave examples of youth who were coerced by gang members into committing crimes, unintentionally provoked police officers, or didn’t know when they were being sexually abused or bullied. Some of the services and supports the panel discussed in conjunction with health and safety are highlighted in table 4.

Table 4: Services Panelists Identified as Supporting Health and Safety Goals of Transitioning Youth with Autism Spectrum Disorders

	Selected aspects of the goal		
	Physical health	Mental health	Safety
Services and supports that may address the needs	Medical services from providers trained about the needs of youth with ASD, including neurodevelopmental medicine, dental care, sleep interventions, reproductive health, and needs of adults	Mental health services from providers trained about the needs of youth with ASD and willing to accept them as patients, access to cognitive behavior therapy and counseling in addition to medication, crisis care, specialized hospitals, and residential treatment facilities	
	Organization and time management coaching on such tasks as making appointments or medication management ^a		Social skills training, mentorship, schoolwide anti-bullying training
	Case management and coordination, including assistance with insurance paperwork, benefits, and finding medical providers		Sexual safety training
	Sexual orientation and gender identity support ^b		Autism training for first responders and law enforcement
	Behavioral or mental health services to reduce self-injurious behaviors and increase emotional regulation		
	Transportation services		
	Coaching or training on medical self-advocacy—explaining symptoms, making sure they are understood ^a		

Source: GAO analysis of roundtable discussion. | GAO-17-109

^aFor the purposes of this report, we have classified these supports under “life skills training and experience.”

^bFor the purposes of this report, we have classified this support under “medical care.”

Goal: Maximizing Community Integration

Community integration includes both individual social interactions and broader community participation. In 2009, according to NLTS2 data, 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.²⁹ The panel noted that community integration is closely tied to higher education and employment because these are where adults tend to establish their social circles. The panel said that having housing, jobs, services, and social opportunities that are located in the community can facilitate interaction with neighbors who do not have ASD and help increase societal acceptance of autism. The panel also described transportation as one of the most important factors in achieving this goal, as it enables physical access to the community, and said that many youth with ASD can use public transportation independently if they

²⁹ Roux et al.

receive adequate training. Table 5 shows some of the services and supports that the panel said may be needed for community integration.

Table 5: Services Panelists Identified as Supporting Community Integration Goals of Transitioning Youth with Autism Spectrum Disorders

	Selected aspects of the goal	
	Social interactions	Community participation
Services and supports that may address the needs	Supports facilitating social connections, such as peer social groups or volunteer programs that bring together youth with and without autism ^a	Supports that facilitate higher education or employment
	Social skills training and practice ^a	
	Personal hygiene coaching or aids ^b	
	Transportation services, including travel training to teach youth how to use transportation independently	
	Communication aids	
	Supports facilitating self-advocacy skills ^b	
	Direct support providers ^c	

Source: GAO analysis of roundtable discussion. | GAO-17-109

^aFor the purposes of this report, we have classified these supports under “social supports.”

^bFor the purposes of this report, we have classified these supports under “life skills training and experience.”

^cFor the purposes of this report, we have classified this support under “medical care.”

Panel Theme: The Need for Access to Evidence-Based Services that Are Individualized, Flexible, Timely, and Provided in the Community

Individualized and Flexible Supports

The panel said that, like other transitioning youth with disabilities, autistic youth need a personalized mix of services that address their unique support needs. Given the individualized and complex nature of ASD, no single combination of supports and services will prepare all youth with

ASD for success as adults, according to the panel. For example, for a successful transition to a higher education environment, one student may need organizational coaching in order to develop study skills, while another may need mental health support for anxiety and peer mentoring in order to attend class every day. According to the panel, having the right combination of supports to meet each person’s individual needs may contribute to success in higher education, employment, community integration, and overall quality of life. The panel also told us that the creation of an individualized support system begins with a comprehensive assessment of a person’s skills and abilities.

On Individualized Supports

“Education, employment, health care, access to communication and self-determination, and support for overall community integration are all critical components for our community. A comprehensive approach which provides individualized, consumer-directed supports in all of these areas can enable all autistic people to participate in their communities, self-advocate, and live meaningful and productive lives with a high quality of life, regardless of level of disability.”

Source: Panelist quotation. | GAO-17-109

The panel said that individuals with ASD need flexible services and supports that can adapt to changes in their needs. Autism is a lifelong disability with characteristics that can shift over time, especially as personal circumstances and comorbid health conditions change. For example, the panel described people whose verbal skills fluctuated from nonverbal to highly fluent during their lifetimes. During their nonverbal periods, they would need communication aids that were not needed during their fluent periods. Additionally, the panel said that the ability to fall and remain asleep could fluctuate over time, and youth may need behavioral therapy or medication during sleepless periods. The panel also cautioned against removing supports that may be needed over the long term. For example, a job coach may be used at the beginning of an autistic person’s employment to help them acclimate to their employer and vice versa. However, the individual may also benefit from continued support—either ongoing or occasional—from a job coach to help address new issues that arise over the course of their employment. Flexible job coaching that was available when needed could help the individual retain the job.

Timely Access to Supports

The panel said that youth with autism need timely access to services and supports, beginning with having enough service providers to meet the demand. For example, according to the panel, youth receiving care from service providers who primarily work with children, such as

developmental pediatricians and speech and language therapists, may need access to adult providers after their transition, because their needs for the service do not necessarily end when they reach a certain age. The panel also said that waiting lists for services have gotten longer due to a “tsunami” of increased demand. Furthermore, due to the unpredictable nature of ASD, there may be times when autistic youth need immediate access to services. For example, if autistic youth become aggressive or self-injurious, they and their families may need such services as emergency rooms, hospitals with specialized units, residential behavioral treatment programs, or direct support providers. Our panel described situations where families lacked immediate access to these services, and hence tried to care for aggressive youth at home, which can risk the safety and well-being of both the person with ASD and others present in the home.

The panel told us that in order for autistic youth to have adequate access to supports, providers of adult services—including basic services important to all adults—would ideally have the expertise necessary to serve clients with autism. For example, dentists may need to be prepared for behaviors often associated with autism, such as the inability to sit in the dental chair, agitation, or self-injury (e.g., head banging). Additionally, according to the panel, youth with autism may have difficulty developing new relationships with service providers and are negatively affected by high turnover rates. The panel noted that support providers who work directly with autistic individuals have a physically and emotionally demanding job and that turnover among these providers is likely related to prevailing wages for this work.

On Provider Expertise

“One of the things we need to do is teach the adult physicians how to deal with adults who have developmental disabilities. Beyond checking their blood sugar and their cholesterol levels and blood pressure, you need to be checking their life. How are they doing psychologically? How is their self-esteem? How are they doing occupationally? And how is their living environment with their families or away from their families?”

Source: Panelist quotation. | GAO-17-109

The panel 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. To avoid gaps, according to the panel, the various programs for adults should have compatible eligibility requirements so that youth do not have to re-establish eligibility. Specifically, the panel said there should be a single point of entry into

adult services, much as the school provides a single point of entry for many services for children. The panel also suggested that transition planning start earlier—as early as middle school—and end when youth turn 25. Finally, the panel noted that autistic youth and their parents need information to help them navigate the adult service system and find the supports they need.

Equitable Access to Supports

The panel said that transitioning youth with ASD should have access to the services they need regardless of their income, geographical location, race, or gender. For instance, the panel told us that low- and middle-income youth with ASD whose families cannot afford to pay for their services out-of-pocket would ideally be able to rely on public programs to help them pay for their adult services—which is not always the case currently. The panel also stated that access to services should not vary depending on the states and communities where youth live. For example, in rural areas, support services like transportation or telemedicine—wherein providers serve patients remotely, such as via video conference—may help improve access to services that are more common in large cities. The panel also discussed the need to maintain a continuum of care as youth move across state lines, noting that even though eligibility rules and service provision may differ from state to state, youths' needs for services and funding do not necessarily change when they move. The panel suggested a portable and flexible funding mechanism that would allow youth to pay for services in any location.

Finally, in order to have equitable opportunities to pursue their adult goals, the panel said that some demographic groups, such as females or minorities, may have specific needs. For example, according to the panel, workplaces may have higher social expectations for women than men, and mentoring from other women on the spectrum could help them learn how to react to these expectations. The panel also noted that girls and minority students are diagnosed with ASD at a later age than other youth, on average—sometimes after they have left high school. As a result, the panel said, they may have received fewer services and may need more help as they transition to adulthood. Additionally, the panel said that minority students—especially those living in low-income, urban areas—may face issues compounded by having less preparation for the transition during their school years, including less parental education on available resources as well as less access to medical care. To address their needs, the panel discussed services such as additional transition planning, education and training for parents on services youth are entitled to, and medical case managers who can help these youth locate, access, and communicate with medical care providers.

Well-Coordinated, Holistic Supports

On Access to Services

"Without transportation, it can be difficult or impossible for autistic youth to hold jobs, pursue higher education, go to community events, meet with peers, access healthcare, or develop relationships, hobbies, or interests outside of the home."

Source: Panelist quotation. | GAO-17-109

According to the panel, services for transitioning youth with ASD should be well-coordinated, with service providers, youth, and their families agreeing on common goals and communicating regularly. The panel told us that, because autism can affect so many aspects of an individual's health and behavior, coordinated care that supports the whole person is particularly important for youth with ASD. For example, according to the panel, an individual needing care from both a mental health practitioner and a developmental disability doctor may not be adequately supported by either provider, because each may assume the other has primary responsibility and thus neither may take a holistic view of the individual's care. Additionally, the panel said that some medical personnel find that other service providers are among the best sources of information about their patients. The panel advocated for a comprehensive approach in which service providers work together to simultaneously address issues of employment, housing, health care, and behavioral health. The panel specifically mentioned two examples of holistic supports: (1) mental health services should be coordinated with other services, such as employment, housing, or education; and (2) medication should be managed in coordination with a person's behavioral health goals and current status.

On Holistic Services

"I think the need is for holism. You really need a team approach with health care, behavioral health, and supported employment. It kind of becomes a necessity that that's a package deal at this point."

Source: Panelist quotation. | GAO-17-109

Community-Based Supports

The panel emphasized the importance of providing services in the community, both by providing some educational services outside the classroom and by locating services in the neighborhoods where youth live. First, the panel 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. Additionally, the panel told us that some youth with ASD may have difficulty making decisions that

depend on changing input. For example, when deciding whether to cross the street, it is not enough to know whether a car is coming. The decision also depends on judging how far away the car is, a factor that continually changes. It is difficult to gain experience making these types of decisions without practicing them experientially.

On Experiential Learning

“Curricula are just words on paper without the supportive environments needed to practice these.”

Source: Panelist quotation. | GAO-17-109

Second, the panel also discussed several benefits of providing services close to youths’ homes:

- Local services may be easier to reach for youth with limited access to transportation.
- Local venues may be more familiar, which may help mitigate difficulties navigating new situations.³⁰
- Local services may help youth better integrate into their community. Rather than youth with ASD becoming known as those who are bused away, receiving services near home may help their neighbors get to know them as members of the community.

On Community-Level Solutions

“I think we need to be fostering community-level solutions. If all of our focus is entirely on clinical interventions for one person at a time, we’re going to be missing the more important questions about how do we create the communities, neighborhoods, and social institutions that are welcoming and inclusive of people with disabilities.”

Source: Panelist quotation. | GAO-17-109

Research Needs

Consistent with our recent work on autism research, the panel emphasized that limited research exists on the service needs of transitioning youth or adults with ASD. In a June 2015 report, we found

³⁰ The Supreme Court has held that mental health services provided by state and local governments must be community-based when the placement is appropriate, the affected persons do not oppose such treatment, and the placement can be reasonably accommodated, taking into account the resources available to the state and the needs of others with mental disabilities. *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 607 (1999).

that research into the needs of adults consistently received less federal funding than other areas of autism research, such as the biology of autism.³¹ Also consistent with our work, the panel said that services should be grounded in evidence-based research and programs should be held accountable for delivering results, but they underscored that more research was needed for this to be feasible. The panel recommended studying the developmental disability system as a whole to determine what large-scale changes may be needed. Some of the specific areas of research they recommended included:

- the needs of transitioning youth and adults with ASD,
- effective adult services,
- interventions for women,
- comorbid conditions and health needs,
- improving collaboration among service providers, and
- efficient uses of funding.

On Need for Research

“I would rather see investments in performance measurement, quality improvement, and accountability that promise to help all people by incentivizing learning systems that aim to continuously experiment and improve...for everyone. The really shocking thing in all this is that we spend roughly \$130 billion per year on services for autism across the lifespan but we have so little insight into who gets what and with what effect.”

Source: Panelist quotation. | GAO-17-109

³¹ GAO, *Federal Autism Research: Updated Information on Funding from Fiscal Years 2008 through 2012*, [GAO-15-583R](#) (Washington, D.C.: June 30, 2015).

Panel Theme: A New Approach to Supporting Youth with Autism to Enhance Their Integration into Society

New Approach to Supporting Youth with ASD

To improve the ability of youth with ASD to fully participate in society, the panel cited the need for a paradigm shift, including a new approach to supports. In this new paradigm, society and autistic youth alike would share the responsibility for inclusion, and the public and service providers would have better understanding of autistic youths' potential. The panel likened this new paradigm to the magnitude of the changes made to physical infrastructure, such as curb cuts, ramps, and elevators, to improve mobility for people with physical disabilities.³²

The panel told us that one element of the new paradigm would be the understanding that the responsibility for the inclusion of autistic youth rests on both the individual with autism and society. The panel said society expects individuals with autism to continually adapt to situations that are difficult for them—even though adaptation itself is difficult for many people with ASD. The panel acknowledged that people with autism are responsible for learning about social expectations for school, work, and social settings, but said that institutions and communities should also learn how best to support individuals with ASD, given the characteristics of autism. For example, the panel said that explaining the “unwritten rules” of workplace social behavior to youth with autism may facilitate their inclusion. On the other hand, the panel emphasized that society should acknowledge that some unwritten rules may lead to the exclusion of autistic youth. For example, the panel noted that it may not be reasonable to expect people with autism to smile or make small talk even though smiling and chatting are often expected in certain situations, such as in the workplace.

On a New Approach to Supporting Youth with Autism:

And if you think about social navigation and autism, and you think about physically navigating a space if you have a mobility difference, what are universal design standards? I don't mean just the structure of a building but what kinds of things could be universally implemented to make those places more accessible for us with our specific disability...so that the onus isn't always on the individual to have to mimic social behaviors that are expected in order to have a standard of living of some kind.

Source: Panelist quotation. | GAO-17-109

³² Curb cuts, ramps, and elevators are examples of physical adjustments made in response to the Americans with Disabilities Act of 1990 (ADA). Pub. L. No. 101-336, 104 Stat. 327 (codified as amended at 42 U.S.C. §§ 12101-12213). This report does not address whether these physical adjustments have been sufficient to meet the needs of those with disabilities in all aspects of society.

Greater Public Understanding of Autism

The panel said that some of the changes they envision might already be supported by federal laws that govern services to people with disabilities, including youth with autism. For example, the panel told us that although existing law requires the provision of experiential learning opportunities for youth with disabilities, including autism, some teachers provide instruction only in a classroom setting despite the benefits of experiential learning.

The panel described how greater public understanding of the characteristics, potential, and challenges of autism would be key to the new paradigm. According to the panel, lack of knowledge about autism can result in misinterpretations of the meanings behind some behaviors. For example, an autistic student with anxiety and depression may miss classes due to those comorbid conditions and may not seek help due to communication difficulties caused by autism. Without an understanding of autism and the behavioral effects of its interaction with comorbid conditions, professors or university personnel may attribute the student's absences to a lack of interest or motivation, underestimate the severity of the situation, and miss an opportunity to help that student. The panel also said a public awareness campaign could deepen the public's understanding of autism and help people think about how they can better support people with ASD. The panel suggested educational sessions that describe the diversity among people with autism, promote tolerance, and help create a safe environment to support youth on the spectrum.

In addition to the wider public, the panel said that professionals who interact with people with autism need education and training about autism. The panel cited a wide range of fields—such as health care, justice, education, transportation, mental health, public safety, and public services—whose members need to understand autism characteristics and be prepared to support them. Specifically, the panel noted that, while youth with autism have clear needs for supports, people should not make assumptions about an individual's competence based on a single characteristic of autism. The panel told us that some people may base their assumptions about the capabilities of an autistic youth on the youth's ability to communicate verbally. For example, people may erroneously equate a lack of verbal communication skills with an inability to make decisions or express preferences, while assuming that those autistic youth who can speak have no communication issues and no need for supports. Consistent with this, the panel noted that those people closest to youth with autism should foster high expectations when preparing them for adulthood. For example, one panelist said that parents and teachers should expect youth to learn to be more independent, noting that people

often adopt a risk-averse approach to teaching autistic youth, coming to the rescue when someone does not succeed at a task. This can create a “learned helplessness” and missed opportunities to teach the valuable life skill of perseverance. Rather, the panel said that youth should begin building self-advocacy skills—identifying and asking for what they need—in middle and high school. For example, one panelist said that youth should learn to identify their sensory, social, and communication differences and strengths.

The new paradigm would include fostering a better understanding of the potential of youth with ASD, according to the panel. Specifically, the panel told us that recognizing the strengths of individuals with ASD can greatly improve their opportunities, while focusing on the difficulties associated with autism may limit them.

On Contributing to Society

These aren't just people who are service users and need things all the time. These are people who can contribute to society, their campus communities. And how do we create opportunities for them to be leaders, to be mentors, as part of the service delivery process?

Source: Panelist quotation. | GAO-17-109

The panel said some characteristics of autism, such as a tendency toward repetitive actions and a preference for routine, could be an advantage in the workplace. For example, the panel told us about a youth who enjoyed stacking boxes—an interest that translated into a job skill needed in the community’s home improvement store—and another young man whose intense focus and interest resulted in encyclopedic knowledge of heating, ventilation and air conditioning. The second youth became the most reliable worker in his internship and reported to work early every day. The panel discussed a national financial services company that initiated an agricultural program for employing youth with disabilities, including autism, because the company saw their comfort with routine and reliability as strengths. The panel also discussed a national retailer that hired workers with disabilities, including autism, and found

that those workers had lower job turnover rates and were just as productive as workers without disabilities.³³

The panel noted that better inclusion of people with ASD could help reduce the stigma associated with autism and reduce bullying, which the panel suggested occurred frequently among youth with ASD. The panel told us that some youth miss out on supports, including helpful medical devices, that may be available to them because they fear being stigmatized if they disclose their autism. A greater understanding of autism in general could decrease the sense of stigma, similar to the way that physical disabilities are becoming less stigmatized over time. In addition, people may be less likely to make flawed judgments or act on stereotypes if they have an increased understanding and acceptance of the different interaction styles characteristic of individuals with autism. The panel noted that one way to reduce bullying was to implement school-based anti-bullying training, that focused on respect and acceptance from pre-kindergarten to 12th grade. Greater public awareness of autism could also improve the safety of autistic youth when they are in the community. For example, the panel discussed the prevalence of abuse, including sexual abuse, among youth with autism and noted that increased awareness of the risks to autistic youth in the community would increase their safety.

On Benefits of Community Awareness and Integration

If someone abused our son, we wouldn't know. He cannot tell us. ...The best safety and security system is more eyes and ears. And so the more people that are coming and going, the more eyes and ears, the more than we are part of community and integrated into community, the better off we are and the safer we will be.

Source: Panelist quotation. | GAO-17-109

Additionally, the panel described the benefits of police officers knowing how to appropriately aid an autistic person who is acting erratically, as well as teaching youth with autism how to interact with the police. The

³³ In 2012, one retailer reported these findings from an evaluation of their workplace inclusion project that was designed to provide work opportunities for people with disabilities, including autism. See Kaletta, James P., Binks, Douglas, J., and Robinson, Richard, Creating an Inclusive Workplace: Integrating Employees with Disabilities into a Distribution Center Environment, *Professional Safety: Journal of the American Society of Safety Engineers*, June 2012.

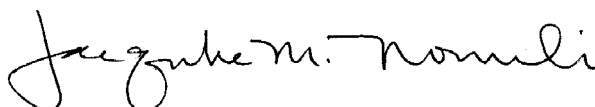
panel said that because some youth with autism may not appropriately respond to verbal commands, increased awareness of autism among police officers was critical given the potential consequences of miscommunication—such as incarceration or violence.

Agency Comments

We provided a draft of this report to Education and HHS for comment. They provided technical comments, which we incorporated as appropriate.

As agreed with your offices, unless you publicly announce the contents of this report earlier, we plan no further distribution until 30 days from the report date. At that time, we will send copies to interested congressional committees and to the Department of Education. In addition, the report will be 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 IV.



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

Appendix I: Objectives, Scope, and Methodology

This is the first in a series of reports on youth with autism transitioning to adulthood. In this report, we focus on describing the needs of transitioning youth with Autism Spectrum Disorder (ASD). A second engagement will examine the services provided to transitioning youth with ASD and any challenges they may face obtaining them.

Objectives

To describe the needs of transitioning youth with ASD, we addressed the following questions:

1. What services and supports do transitioning youth with autism need to attain their goals for adulthood?
2. What are the characteristics of needed services and supports?
3. How can youth with autism be fully integrated into society?

Choosing Panelists

To answer our research questions, we convened a roundtable discussion on March 3 and 4, 2016. We selected a total of 24 panelists,¹ including:

- autistic adults;
- service providers, including teachers, developmental pediatricians, transition specialists, behavioral therapists, and leaders of programs providing employment supports, college supports, legal representation, social supports, and residential supports, among others;
- employers who provide supports for workers with autism;
- researchers; and
- parents of youth and adults with autism with a range of ages and support needs.

Most panelists fell into more than one of these categories. We chose panelists based on the following:

- their expertise about autism, as measured by their personal or professional experience with autism or participation on relevant

¹ Of the 24 individuals who comprised our panel, two were not present at the roundtable discussion.

Boards of Directors or the Interagency Autism Coordinating Committee;²

- recommendations from others with subject matter knowledge, including researchers and organizations we interviewed during our background research as well as other panelists; and
- backgrounds and perspectives reflecting the diversity of the autism community, including variations in service areas, income, race, gender, geographic location, and urbanicity. We considered panelists' personal backgrounds as well as the autistic populations they worked with.

The full list of panelists is included in the agenda in appendix II.

Panel Topics of Discussion

We asked the panel about the services that transitioning youth across the autism spectrum need to help them achieve five goals for adulthood:

1. Postsecondary education.
2. Employment.
3. Maximizing independent living.
4. Health and safety.
5. Maximizing community integration.

We chose these goals because they were either listed in the transition planning requirements for high school students receiving special education services (goals 1, 2, and 3)³ or described by potential panelists in pre-selection interviews as particularly important (goals 4 and 5).

To guide our discussion, we asked the panel the following questions about each of the five goals:

- What autism characteristics impede or facilitate achieving the goal?
- What services/supports/institutional changes help youth manage or leverage those characteristics?

² The Interagency Autism Coordinating Committee is a federal advisory committee charged with monitoring and coordinating federal autism research.

³ See the background section for more information about special education and transition planning requirements.

-
- What happens when youth receive each service/support?
 - What happens when they do not receive it?
 - Have we discussed youth with the greatest, moderate, and least needs for each service/support?
 - Are there special considerations for young women, minorities, low-income youth, rural youth, or other groups?

We asked the panel to describe services ideally needed for a successful transition to adulthood, regardless of what services may currently be available or feasible. We did not verify the accuracy of the information they provided. The panel also pointed out that many of the services needed to support youth with ASD may also support youth with other disabilities. While we focus on how these services would particularly address characteristics associated with autism, the panel also cautioned against singling out autistic youth unnecessarily.

Appendix II includes the agenda for the panel including a list of invited panelists. Of the 24 panelists, 2 were not present at the actual event, including an autistic individual who does not use spoken language. We interviewed them afterward to obtain their thoughts on the same topics covered during the panel and included this information in our analysis. We asked panelists to provide comments on a draft of this report, which we incorporated as appropriate.

Analysis of Information from the Panel

We conducted a content analysis of the transcript of the 2-day event as well as documents the panelists submitted in writing to clarify and support information discussed during the panel meeting. Specifically, we used the NVivo qualitative analysis software to classify each sentence into one or more categories, depending on whether the speaker was discussing:

- One or more of the five goals for adulthood;
- One or more services; or
- One or more of several cross-cutting needs—issues that applied across services or goals.

We identified these categories by creating lists of all the services and cross-cutting issues the panel mentioned at least once during the discussion or in the documents. For brevity and organizational purposes, we then grouped them into broader categories based on their relatedness and our understanding of autism services garnered from literature and interviews. This process resulted in 14 broad categories of services,

which are listed and described in appendix III,⁴ and 13 categories of cross-cutting needs:

- public awareness of autism;
- service provider awareness of autism;
- new paradigm;
- sufficient access to supports;
- individualized supports;
- adequate and flexible funding;
- coordination among service providers;
- service provider accountability;
- staff quality and training;
- service quality;
- research needs;
- equity issues for specific groups; and
- other cross-cutting issues.

Two analysts categorized the sentences in NVivo. To ensure consistency, both analysts classified the same sample of the transcript and a reliability analysis determined that they chose the same categories over 95 percent of the time. Each analyst also spot checked the other's work. After categorizing the sentences, we analyzed the text in each category to identify the emerging themes. We attribute these themes, as well as specific examples given for illustrative purposes, to "the panel" throughout this report.

For convenience, we use the term "youth" in this report to describe individuals aged 14 to 24, the age range when they may be eligible for transition services, depending on their state. This age range is in keeping with our previous work as well as other federal programs and organizations. During the transition years, youth may receive services for children, adults, or both.

⁴ The actual range of services provided under these broad categories could be wide, with much variation in method, purpose, philosophy, and effectiveness.

Appendix II: Agenda and List of Invited Panelists



U.S. GOVERNMENT ACCOUNTABILITY OFFICE

AGENDA

GAO Expert Panel: Youth with Autism Transitioning to Adulthood

March 3, 2016

8:30 am – 4 pm

Staats Briefing Room

Moderated by Walter Vance and Farrah Graham

8:00 am – 8:30 am	Arrivals/Check In <i>Continental Breakfast</i>
8:30 am – 8:40 am	Welcome and Opening Remarks <i>Barbara Bovbjerg, Managing Director</i> <i>Education, Workforce and Income Security Issues</i>
8:40 am – 8:50 am	Ground Rules <i>Walter Vance</i>
8:50 am – 10:00 am	Panelist Introductory Statements
10:00 am – 10:20 am	Break
10:20 am – 12:00 pm	Discussion: Services Needed to Succeed in Postsecondary Education
12:00 pm – 12:40 pm	Lunch <i>McCarl Room</i>
12:40 pm – 2:20 pm	Discussion: Services and Supports Needed to Obtain and Maintain Employment
2:20 pm – 2:40 pm	Break
2:40 pm – 3:20 pm	Continued Discussion: Services and Supports Needed to Obtain and Maintain Employment
3:20 pm – 4:00 pm	Discussion: The Role of Specialized Employment (Sheltered Workshops)



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PANELISTS

GAO Expert Panel: Youth with Autism Transitioning to Adulthood March 3, 2016

Anshu Batra, MD, F.A.A.P
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Our Special Kids Pediatric Care
Parent of a young adult with ASD

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Ventures
Board Member, Autism Society of America
Parent of an adult with autism

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Parent of a teen son on the spectrum

Valerie Paradiz, PhD
President, Valerie Paradiz, LLC
Individual with autism and parent of two
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Associate Professor
Leader - Life Course Outcomes Research
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A.J. Drexel Autism Institute

John Stewart
Transition Coordinator
Henrico County Public Schools
Parent of a child with autism

Julie Lounds Taylor, PhD
Assistant Professor
Vanderbilt University
Vanderbilt Kennedy Center Investigator



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AGENDA

GAO Expert Panel: Youth with Autism Transitioning to Adulthood

March 4, 2016

8:30 am – 4 pm

Staats Briefing Room

Moderated by Walter Vance

8:00 am – 8:30 am	Arrivals/Check In <i>Continental Breakfast</i>
8:30 am – 8:40 am	Welcome and Opening Remarks <i>Barbara Bovbjerg, Managing Director</i> <i>Education, Workforce and Income Security Issues</i>
8:40 am – 8:50 am	Ground Rules <i>Walter Vance</i>
8:50 am – 10:00 am	Panelist Introductory Statements
10:00 am – 10:20 am	Break
10:20 am – 12:00 pm	Discussion: Services Needed to Reach Maximum Independence
12:00 pm – 12:40 pm	Lunch <i>McCarl Room</i>
12:40 pm – 2:40 pm	Discussion: Services Needed to Maintain Physical and Mental Well-Being <i>Physical Health, Mental Health, Sexual Health, Safety</i>
2:40 pm – 3:00 pm	Break
3:00 pm – 4:00 pm	Discussion: Services Needed to Maximize Community Integration



U.S. GOVERNMENT ACCOUNTABILITY OFFICE

PANELISTS

GAO Expert Panel: Youth with Autism Transitioning to Adulthood March 4, 2016

Julia Bascom

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Executive Director
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Executive Director
Felicity House

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Developmental Pediatrician
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Appendix III: Services and Supports for Transitioning Youth with Autism Identified By the Panel

The panel identified 14 broad categories of services and supports that may help youth with Autism Spectrum Disorders (ASD) attain the goals of education, employment, health/safety, independent living, and community integration as they transition to adulthood. Table 6 shows which services may support each goal, according to the panel. Figures 3 through 16 illustrate the same information, as we describe each service.

Table 6: Services that Support five Goals that Youth with Autism Spectrum Disorders (ASD) May Pursue in Adulthood, According to the Panel

Service	Goal for Adulthood that Youth with ASD May Pursue				
	Postsecondary Education	Employment	Maximizing Independent Living	Health and Safety	Maximizing Community Integration
Behavioral Interventions	a	a	a	•	a
Case Management/Coordination	•	•	•	•	•
Communication Services	•	•	•	•	•
Day Programming	○	○	b	•	○
Family Education and Supports	•	•	•	•	•
Life Skills Education and Experience	•	•	•	•	•
Medical Care	•	•	•	•	•
Mental Health Care	•	•	•	•	•
Postsecondary Education Planning and Supports	•	○	○	○	•
Residential Supports	•	•	•	•	•
Social Supports	•	•	•	•	•
Transition Planning Services	•	•	•	•	•
Transportation Supports	•	•	•	•	•
Vocational Supports	○	•	•	○	•

- Service generally supports goal
- Service does not generally support goal

Source: GAO analysis of roundtable discussion. | GAO-17-109

^aPanelists disagreed about the effectiveness of behavioral interventions. Some felt that behavioral interventions can help people of all ages with a variety of goals, including the 5 that we discussed. Others said that behavioral interventions are not helpful or even harmful for adults.

^bPanelists told us that, although some day programs are intended to provide life skills instruction, day programs are variable and as a whole they do not reliably contribute to maximizing independent living.

Behavioral Interventions

Figure 3: Roundtable Views of Goals Supported by Behavioral Services



Source: GAO analysis of roundtable discussion. | GAO-17-109

Behavioral interventions are treatments intended to help autistic youth develop skills and reduce challenging behaviors. Behavioral 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 in order to manage responses to them. 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. Panelists strongly disagreed about its efficacy in adults.

Case Management/Coordination

Figure 4: Roundtable Views of Goals Supported by Case management/Coordination



Source: GAO analysis of roundtable discussion. | GAO-17-109

Case management and coordination services help people with autism navigate the multiple agencies and organizations that provide services, including vocational, educational, housing and life skills supports, among others. Case managers/coordinators do not provide the actual services themselves, rather, they provide information about the adult disability system, including the different eligibility criteria for the multiple agencies that provide services, and the managed health care system, including requirements for insurance coverage.

Communication Services

Figure 5: Roundtable Views of Goals Supported by Communication Services



Source: GAO analysis of roundtable discussion. | GAO-17-109

Communication services can include aids or instruction to help nonverbal and verbal autistic youth communicate. For example, nonverbal youth may be able to point to pictures or letters on charts or use a smart phone, tablet, computer, or device designed specifically to provide speech functions. Communication services also include training on how to use communicative aids and support while using them.

Day Programming

Figure 6: Roundtable Views of Goals Supported by Day Programming



Source: GAO analysis of roundtable discussion. | GAO-17-109

Day programs provide supervision and activities for individuals who have exited the school system. Some are designed to provide instruction in life skills, community activities, or therapy, but the panel said that their actual operations are highly variable and more often segregated from the community.

Family Education and Supports

Figure 7: Roundtable Views of Goals Supported by Family Education and Supports



Source: GAO analysis of roundtable discussion. | GAO-17-109

Families may play many roles in the lives of youth with ASD and may utilize a variety of supports. Training may help families learn how to access available resources, teach life skills, use communication aids, or identify mental health needs. In addition, some families may utilize social support from peers who understand their situations or may use respite services—short-term supervision for youth with ASD. Additionally, when youth turn 18, they and their families may need assistance making decisions about the legal aspects of adulthood, such as who will have access to their medical information or the ability to make financial or medical decisions.

Life Skills Education and Experience

Figure 8: Roundtable Views of Goals Supported by Life Skills Education and Experience



Source: GAO analysis of roundtable discussion. | GAO-17-109

Life skills include daily living skills, executive functioning, and self-advocacy. Daily living skills include household tasks, personal care, nutrition, and personal finance. Executive functioning includes organizing, planning, managing time, sequencing tasks, self-control, and adapting to change. Self-advocacy is the ability to understand one's own needs and take action to meet them. Youth can learn these skills through training, coaching, and practice. Additionally, tools such as schedules, organizers, and visual prompts can help youth with autism improve their life skills.

Medical Care

Figure 9: Roundtable Views of Goals Supported by Medical Care Services



Source: GAO analysis of roundtable discussion. | GAO-17-109

Youth with autism have many of the same medical needs as other youth, but there are some areas where they have particular needs or may have difficulty locating providers with the expertise to treat patients with ASD.

- Autism assessments identify an individual's autism characteristics and help youth, their families, and service providers plan for appropriate supports.
- Dental care can be a particularly challenging aspect of health care for many youth with ASD. Dentists may need to provide specific supports and devote extra time when treating patients exhibiting some of the behaviors of ASD, such as refusing to sit in the examination chair.
- Personal support providers work one-on-one with autistic youth to provide supervision and assist youth with their daily needs, such as medication, therapy, recreation, and transportation.
- Sexual health care includes reproductive care; education about puberty, sexual safety, and preventing exploitation and abuse; and trauma care after abuse.
- Sleep medicine includes evaluations and treatment for sleep issues, which are common among individuals with ASD and may manifest differently than in the general population.
- Therapeutic services may include speech/language, occupational, and physical therapy, among others.

Mental Health Care

Figure 10: Roundtable Views of Goals Supported by Mental Health Care Services



Source: GAO analysis of roundtable discussion. | GAO-17-109

Counseling, therapy, and medication can help youth with ASD manage comorbid mental health conditions. Mental health conditions may manifest differently in people with ASD, and they need providers who can distinguish mental health symptoms from the characteristics of autism.

Postsecondary Education Supports

Figure 11: Roundtable Views of Goals Supported by Postsecondary Education Supports



Source: GAO analysis of roundtable discussion. | GAO-17-109

Postsecondary education supports are intended to help youth with ASD succeed in a variety of postsecondary settings, including community colleges, 4-year universities, and vocational or technical schools. Academic supports include, for example, extended test-taking time, assistance with note-taking in class, and delivery of instructional material in various formats to support differences in learning styles. In addition, education supports can help autistic youth with skills such as organization as self-advocacy, which can also be important to success in postsecondary education programs.

Residential Supports

Figure 12: Roundtable Views of Goals Supported by Residential Supports



Source: GAO analysis of roundtable discussion. | GAO-17-109

Residential supports may range from assistance with housekeeping to 24-hour onsite support. These supports may be chosen and hired by an adult with autism, or they may be provided by a housing facility. For adults with ASD who do not live on their own or with family, there are many residential housing models that vary by size, degree of community integration, and intensity of supports. For instance, one short-term residential model provides life skills education and experience to help youth transition to more independent living. A second model is a more permanent home that provides onsite employment opportunities, as well as other supports. A more intensive type of residential setting provides behavioral and medical services and supports.

Social Supports

Figure 13: Roundtable Views of Goals Supported by Social Supports



Source: GAO analysis of roundtable discussion. | GAO-17-109

Social supports are intended to help individuals with ASD successfully interact with others. Some supports give youth with ASD opportunities to socialize with others or learn social skills, such as training and coaching in interpersonal skills and social expectations, peer support and mentoring by others with ASD, and structured social groups, events, or camps for youth both with and without autism. Other services are for people who interact with youth with ASD, such as guidance on how to make institutions welcoming and safe for people with autism or school-wide anti-bullying and social skills training.

Transition Planning Services

Figure 14: Roundtable Views of Goals Supported by Transition Planning Services



Source: GAO analysis of roundtable discussion. | GAO-17-109

Transition planning services help autistic youth identify their goals for adulthood and create a plan for achieving them, including obtaining the services and supports they will need to accomplish those goals. Initially, transition planning services are provided in high school by a student’s Individual Education Program team—teachers, school administrators, the student, parents, and service providers. Transition planning can also continue after high school in settings designed to provide that service.

Transportation Supports

Figure 15: Roundtable Views of Goals Supported by Transportation Supports



Source: GAO analysis of roundtable discussion. | GAO-17-109

Many youth with ASD do not drive, and some may have difficulty navigating public transportation on their own or may live in areas with no public transportation. For these youth, transportation services can be critical for accessing community events, obtaining employment or education, maintaining friendships, or leaving their homes for any other reason. Transportation supports can include reduced public transportation fares, paratransit services that provide on-demand, door-to-door service or fixed-route services to specific locations like grocery stores or hospitals, volunteers who drive clients to their destinations, travel training on skills such as navigating public transit and other mobility services, adaptive driver’s education courses, and assistive technology for navigation.

Vocational Supports

Figure 16: Roundtable Views of Goals Supported by Vocational Supports



Source: GAO analysis of roundtable discussion. | GAO-17-109

Vocational supports may facilitate employment for youth with ASD. Examples include:

- vocational assessments to identify the specific supports a youth needs, based on their individual autism characteristics, skills, strengths, and preferences;
- vocational training;
- assistance finding careers that are a good match for youths' interests and skills;
- job search, application and interviewing assistance;
- employer supports, such as incentives to hire employees with disabilities, facilitation of communication with autistic employees, and education about autism and how to work with an autistic employee;
- self-employment assistance; and
- job coaches to provide support in the workplace.

Appendix IV: GAO Contact and Staff Acknowledgements

GAO Contact

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Staff Acknowledgements

In addition to the contact named above, Nagla'a El-Hodiri (Assistant Director); Brittni Milam (Analyst in Charge), Sandra Baxter, Farrah Graham, and Walter Vance made key contributions to this report. Also contributing to this report were: James Bennett, Holly Dye, David Forgosh, Flavio Martinez, Daniel Meyer, Sheila McCoy, Arthur Merriam, Vernetta Shaw, and Adam Wendel.

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