Transition from School to Work for Students with Autism Spectrum Disorders: Understanding the Process and Achieving Better Outcomes

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- Autism spectrum disorders Early adulthood
- Social competence Employment models

Darius was diagnosed with autism when he was 6 years old. He displayed all of the classic characteristics of the disorder around the age of 3, but his physician was uncomfortable with the disorder and reluctant to "label" Darius at such a young age. Specifically, Darius spoke his first word at 2 years old. By 3, he was using oneword phrases. He did not like playing with others and did not play pretend ever. Instead, he stacked blocks while watching the same part of a children's movie repeatedly. He was a difficult child as well. His parents struggled to get everyday community activities done because he screamed and cried whenever his daily routine changed. As a young child with a communication delay, he received 1 hour of speech therapy per week from an early-intervention provider. The early-intervention provider met with the family and child care providers, and taught them to withhold items he wanted

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until he named the item he wanted. By the time Darius entered school; he used twoword phrases to request items and repeated verbatim sections of dialogue from his favorite children's movie.

Once he entered school, Darius' school team prepared an Individualized Education Program (IEP) and served him as a child with autism. At that point, Darius' physician also diagnosed him with autism. When meeting with the doctor, Darius' parents had many questions for the medical professionals about his future. The parents wondered whether Darius would be able to get a job, live independently, have a girlfriend, and partake in all the other activities that most other individuals without disabilities experience; they asked their family physician about Darius' future and asked what they should do to plan for his life. The physician did not have many answers for them. In fact, she was not even sure what to tell them about planning for Darius' schooling. Instead, she suggested that they talk to the school psychologist in his special education program. After turning to the school psychologist and the other medical and psychological professionals, the parents still did not have many answers about how to plan for Darius' future, so decided to take his educational and behavioral treatment year by year and leave their worries about his future for later.

Throughout his schooling, Darius did make progress. For example, he acquired more language, albeit with a loud, pedantic voice tone. He learned to read and complete simple mathematical problems to a third-grade level. Because of a new practice called inclusion, Darius also had the opportunity to attend some classes with his peers without disabilities. During these classes, he displayed somewhat more flexibility in respect of his daily routines. At home, he continued to spend his free time watching sections of the same movie repeatedly. As he entered high school, he continued to work on academic skills and activities designed for elementary school children. Because of the progress he made through his school career, as a 20-year-old young adult he did not display the classic signs of autism that were present at the age of 3; nevertheless, he continued to display many characteristics typical of adolescents and adults with autism spectrum disorders (ASD). 1

Darius desires to live a full and connected life in his adulthood. He represents the beginning of a wave of students with ASD who are entering adolescence. As the measured incidence of ASD has increased, most of the research available to describe evidence-based practices has focused on young children between the ages of 3 and 6 years. At the same time, many more individuals will enter adolescence and young adulthood in the coming years. It is essential to increase understanding of the essential elements of support necessary to assist Darius and his peers with ASD in successfully transitioning from school to adulthood. In other words, while Darius is still in school it is important to redesign his school program to prepare him for adult life. Thus, the purpose of this article is to: (a) describe the characteristics of autism in adolescence and young adulthood, (b) identify the needs of individuals with ASD as they transition from school services to adulthood, (c) describe the employment supports and models for adults with ASD, and (d) discuss implications of these supports for medical professionals.

THE CHARACTERISTICS OF ASD IN ADOLESCENCE AND EARLY ADULTHOOD

ASD is a behavioral disorder that includes deficits in communication and social interaction, and a series of behaviors described as "repetitive, restricted, and stereotyped patters of behaviors, activities, and interests." Darius displays many of these characteristics, as described above. Specifically, he continues to display challenges related

to communication and social interaction. He also continues to rely on routines to guide his behavior, even with some increased flexibility.

As individuals with ASD move into adolescence, the characteristics associated with ASD change somewhat. Specifically, individuals with ASD, like Darius, who have had the opportunity to interact with their peers without disabilities, demonstrate improved communication and social interaction. In addition, there may be a lessening of the impact of the restricted behaviors associated with the disorder. Thus, by adolescence many of the original symptoms that lead to initial concerns abate somewhat. Nevertheless, Seltzer and colleagues suggest that, while there is an abatement of symptoms, the developmental trajectory for individuals with ASD is splintered, with improvement in some behaviors that define autism. These investigators also note that some individuals with ASD experience periods of regression in the areas of behavioral challenges and insistence of sameness. Finally, they note that some individuals experience a worsening of symptoms. Thus, the developmental trajectory for individuals with ASD through adolescence is neither uniform nor linearly ascending. Seltzer and colleagues report findings indicating improvement in communication; however, continued impairment, particularly in social communication, persists into adulthood.

Gilchrist and colleagues⁸ found that by adolescence, individuals with Asperger syndrome show similar behavioral characteristics to individuals with high-functioning autism in adolescence. These investigators found that delays in language development for individuals with high-functioning autism were ameliorated by adolescence, leading to the finding that individuals with Asperger disorder were similar to individuals with high-functioning autism. This final point adds support to the proposed changes in the *Diagnostic and Statistical Manual of Mental Disorders*, Fifth Edition (DSM-V). In fact, proposed changes to DSM-V include the elimination of Asperger disorder as a separate diagnosis (Proposed Revision, APA DSM-5, unpublished data, 2011). Though controversial, it appears that this change will not result in significant changes related to diagnosis in adolescence. In addition, the American Psychological Association proposes a change from 4 symptom categories to 3. **Table 1** shows the proposed changes to the diagnosis of ASD between the *Diagnostic and Statistical Manual of Mental Disorders*, Fourth Edition, Text Revised (DSM-IV-TR) and DSM-V.

These changes in diagnostic requirement are likely to have little impact on adolescents, with a few exceptions. First, it is possible that some adolescents did not present the full characteristics of ASD under the old criteria, but will present as such under the new diagnostic criteria. Second, the loosening of the age of onset of symptoms is likely to assist diagnosticians in identifying individuals with symptoms after early childhood. Finally, the merging of deficits in social and communication abilities into one symptom category may decrease the emphasis placed on symptoms, such as nonverbal communication, that are both social and communicative in nature.

In addition to these primary diagnostic symptoms, there are secondary symptoms that can be as impactful and debilitating as the primary characteristics. Such indications include mental health diagnoses and behavioral challenges. In fact, there is evidence that adolescents with ASD are at greater risk of experiencing depression and anxiety disorders. ^{11–13} Finally, the combination of primary and secondary characteristics affects individuals' abilities to adapt and be successful at work, at home, and in relationships with others. Consequently, individuals with ASD have experienced lower rates of success in adulthood than those with other types of disabilities. Research indicates that adults with ASD are chronically unemployed and underemployed at relatively high rates. ^{14–18} Nevertheless, individuals with ASD can achieve employment and independence in life when provided with a personal goal-focused

Characteristic	Current Characteristics in DSM-IV-TR	Proposed Changes in DSM-V	Description of Proposed Changes
Title of disorders	Pervasive Developmental Disorders	Autism Spectrum Disorder	Placing Autism in name of category and including the word "spectrum" in title
Disorders included in category	Autism, Pervasive Developmental Disorder Not Otherwise Specified, Asperger Disorder, Rett Disorder, Childhood Disintegrative Disorder	Autism Spectrum Disorder with notation of severity across symptoms, Level 1 "requiring support," Level 2 "requiring substantial support," Level 3 "requiring very substantial support"	Rett Disorder will be categorized as a medical disorder and therefore removed from the DSM altogether. All other disorders will be considered "autism spectrum disorder." Levels of intensity of support noted across symptoms
Deficits in communication	Qualitative Impairment in Communication: Four different symptom descriptions, diagnosis required at least 1 of the 4 noted symptoms	This category is combined with deficits in social interaction to become "Persistent deficits in social communication" There are 3 symptom areas. Must meet criteria for all 3 of the descriptions	The notation of communication deficits becomes a part of the behaviors described under "Persistent deficits in social communication"
Deficits in social interaction	Qualitative Impairment in Social Interaction: Four different symptom descriptions, diagnosis required at least 2 of the 4	This category is combined with deficits in communication to become "Persistent deficits in social communication" There are 3 symptom areas. Must meet criteria for all 3 of the descriptions	The notation of social interaction deficits becomes a part of the behaviors described under "Persistent deficits in social communication"
Excessive repetitive behaviors, routines, activities, and interests	Restricted, Repetitive, and Stereotyped Patterns of Behavior, Activities and Interests: Four different descriptions of behaviors, Diagnosis required 1 of the 4 descriptions	Restricted, Repetitive Patterns of Behavior, Interests and Activities: Four different descriptions of behaviors. List now includes "Hypo or Hyper reactivity to sensory input," Must meet criteria for at least 2 of the 4 descriptions	The only major change in this category is the inclusion of different responses to sensory input
Age of onset	Onset prior to age 3 y	Onset in early childhood while noting that symptoms may not be fully manifested until demands exceed capacity	Slight loosening of the age of onset with the notation that symptoms may not be salient until social demands exceed individual's ability to respond

From Proposed revision, APA DSM-V. Available at: http://www.dsm5.org/ProposedRevision/Pages/proposedrevision.aspx?rid=94. Accessed June 15, 2011.

curriculum and intensive structured instruction. 1,19-22 The next section of describes the elements of quality transition programs for adolescents and young adults with ASD.

TRANSITION NEEDS FOR YOUTH WITH ASD

Much of the early research on children with ASD has focused on the younger ages, with less attention to the transition issues and challenges they face. ²³ According to the US Department of Education there are 6,608,446 youths in special education, with 10% between 14 and 21 years of age. ²⁴ It is known that more than 90% are unemployed on exiting school ¹⁷ and that relatively few go to college and complete a degree. In addition, it is known that as these children become adolescents they are among the most expensive to rehabilitate through the federal state vocational rehabilitation program, as well as having among the poorest outcomes. ²⁵ The vocational rehabilitation system in the United States has not considered young people with ASD as good candidates for employment.

Transition has been defined in the Individuals with Disabilities Education Act (IDEA) 2004 as follows.

Transition services mean a coordinated set of activities for a student with a disability that:

- A. is designed to be within a results-oriented process, that is focused on improving the academic and functional achievement of the student with a disability to facilitate the student's movement from school to postschool activities, including:
 - · postsecondary education,
 - · vocational education,
 - integrated employment (including supported employment),
 - continuing and adult education,
 - · adult services,
 - independent living, or community participation;
- B. is based on the individual student's needs, taking into account the student's strengths, preferences and interests; and
- C. includes instruction, related services, community experiences, the development of employment and other postschool adult living objectives, and, if appropriate, acquisition of daily living skills and functional vocational evaluation (IDEA; 2004 [34 CFR 300.43(a)] [20 U.S.C. 1401(34)].

IEPs for students aged 16 years and older must reflect specific transition planning. Some states (Virginia, Delaware, Rhode Island) have moved this to age 14. According to IDEA, the IEP must include a statement of

- appropriate measurable postsecondary goals based on age-appropriate transition assessments related to training, education, employment and where appropriate, independent living skills;
- the transition services (including courses of study) needed to assist the (student) in reaching those goals [34 CFR 300.320(b) and (c)] [20 U.S.C. 1414 (d)(1)(A)(i)(VIII)].

TRANSITION OUTCOMES

Public education has not been very effective in meeting the needs of adolescents and young adults with ASD, as the aforementioned data demonstrate. A primary source of information about postsecondary outcomes for students with ASD is the National

Longitudinal Transition Study 2 (NLTS2). The NLTS2 followed a large representative sample of youth enrolled in special education as they transitioned into young adulthood from 2001 to 2009, with a cumulative age range of 13 to 26 years. From the overall sample (N = 11,000), 922 youths were from the autism category. Newman and colleagues¹⁷ reported that students with ASD only participated in general education about 33% of the time, with most coursework provided in special education (62%). Even though the majority of time modifications to the curriculum were in place in general education settings, students with ASD were substantially less engaged than their typical peers in general education settings. In a recent study, Shattuck and colleagues²⁶ examined patterns of service use among youth with ASD from the NLTS2 sample. Data analysis on youth who exited high school revealed that 32% attended postsecondary education schools, 6% had competitive jobs, and 21% had no employment or education experiences at all. Further, 80% of these individuals were living with their parents, 40% reported having no friends, and only 36% had a driver's license. Unfortunately, youth from families with lower socioeconomic levels had worse outcomes on all measures.²⁶

Hence, the question becomes what can help influence these outcomes in a more positive manner? Some educational practices are favorably associated with better outcomes. The next section describes such practices.

FACTORS ASSOCIATED WITH FAVORABLE TRANSITION OUTCOMES Vocational Competence and Employment Perspective

Vocational capacity, employment, and the opportunity to advance in a career is a major underpinning of success in American society.²⁷ Adults frequently describe their success by their earning ability, the type of work that they do, the regularity with which they are employed, the type of environment in which they work, and their long-term work potential. It is known that those youths with ASD who work in school are more likely to be employed as adults.^{28,29} Thus, the first practice associated with favorable transition outcomes is the design of high school internships that result in employment before the individual graduates from high school. It is critical that educators and community support programs emphasize employment as a desired and measured outcome prior to graduation from high school.

Implementing Evidenced-Based Practices that Increase Independence

The use of the Internet, automation, greater efficiency in the workplace, and technology enhance the success of all workers. Youth with ASD can be empowered in the workplace with the use of equipment such as smart phones and personal digital assistants.³⁰ In addition, educators and community support staff must increase access to programs implementing scientifically based practice for this age group.³¹ At the same time, there is a need for more research toward defining program practices and design that result in employment outcomes for students with ASD. While this literature is growing, it is not currently meeting the needs of the educational community to provide guidance for those students currently in school. The discovery and implementation of evidence-based practices are essential in improving student learning so that individuals with ASD can maximize their work capacity in American society.^{2,3}

Increasing Social Competence

Many believe that demonstrating interpersonal skills and social competence in a variety of environments are the most important features of success in life. Unfortunately, many young people with ASD are ultimately unable to achieve this level of competence.²⁰ Using effective social skills and knowing how to behave in a variety of social situations can make the difference in successful outcomes in the workplace as well as at home and in the community. Youth with ASD who are verbally inappropriate most likely will not develop effective social relationships. Many of the precipitating factors that lead to problem behaviors in the classroom are predicated on poor social skills. On the other hand, using practices such as role playing, counseling, behavior rehearsal, and targeted instruction on social skills frequently results in overcoming the problems associated with poor social skills. Social competence and the demonstration of positive social skills are critical to successful transition.

Self-Determination and Self-Advocacy

Self-determination is the capacity to choose and to act based on those choices. In addition, individuals who are self-determined can make plans and adjust those plans based on circumstances beyond their control. For individuals with ASD, self-determination results in individuals being able to identify their strengths, preferences, and interests, and to identify potential careers that match their strengths and interests. The emphasis on self-determination for people with ASD and other disabilities can be traced to the independent living and self-advocacy movements that emerged in the 1970s. Most people develop self-determination in childhood and adolescence as they receive greater responsibilities and freedom from their parents and teachers. Individuals cannot self-advocate if they have not developed self-determination skills. Self-advocacy ultimately will be the way for young people with ASD to navigate the challenges they face as they enter adulthood.

Self-determination requires that the teenager with ASD learn the knowledge, demonstrate the competency, and identify the opportunities necessary to exercise freedom and choice in ways that are valuable to him or her. Little doubt remains that those people who are self-directed, and have the initiative and ambition to be successful while also practicing a reasonable degree of work ethic do better in life than those who do not.³⁴ There is, of course, room for debate regarding how much the schools are able to instill these important skills.³⁵ Self-determination is related to personal attributes that result in better outcomes for students with ASD.³⁶ Therefore, curriculums that result in increased self-determination are an important aspect of transition programs.

Parental Involvement

In a word, good parents are awesome. Good parents do make a difference, with their values and their contacts in the community and workplace. For a student with ASD seeking employment on graduation, the family and extended family play a very important role. The transition to adulthood is both an exciting and challenging time for youth with ASD and their families. Although this period is critical for all individuals, for people with autism the development of appropriate supports during the transition process is crucial. Indeed, individuals with ASD may be described by the supports they need in relation to the demands in specific environments. For example, these individuals may have support needs in areas of intellectual functioning, adaptive skills, motor development, sensory functioning, health care, or communication. These areas necessitate identifying strategies and supports that will assist these individuals in being successful and achieving desired outcomes. The family frequently acts as case manger and the conduit through which many of these needs are identified and skills practiced. Transition programs that result in excellent outcomes for youth with ASD involve families in the process throughout the youth's school years.

School and Community Inclusion

The inclusion of students with disabilities into general education classrooms is a substantiated transition best practice. Young people with disabilities cannot feel part of a high school if they do not have access to the general curriculum, interact with students in the school, participate in extracurricular activities, and abide by the school rules. Working in real jobs, shopping, and volunteering in the community cannot be preformed competently without the foundation of being in a regular school. Perhaps one of the most useful applications of the original school "mainstreaming" concept has been collaborative teaching. In this approach a special education teacher or paraprofessional works collaboratively in the general education classroom with the regular education teacher. This collaboration can take place in a tutoring mode, a team teaching mode, or any collaboration model that benefits the students with ASD who are in the classroom.

According to Snell and Janney³⁷:

The nature of high schools present greater obstacles for co-teachers because of the emphasis on content area knowledge, the need for independent study skills, the faster pacing of instruction, high-stakes testing, high school competency exams, less positive attitudes of teachers, and the inconsistent success of strategies that were effective at the elementary level. (p. 36)

Despite these points, the fact remains that collaborative teaching opens up the doors for students to have many more opportunities to interact with nondisabled students and general education teachers. This forward step results in higher expectations of students with ASD, higher aspirations by parents, greater access to activities with their nondisabled peers, and a much richer set of opportunities for enhanced self-esteem and adjustment.³⁸

Postsecondary Education

A final theme that continually emerges in successful transition outcomes is the need for postsecondary education.³⁹ Many individuals with disabilities have difficulty in the workplace throughout their lives, and also have difficulty with social skills and personal self-esteem. One way to overcome such drawbacks is education. Earning an associate's degree or a bachelor's degree from a 4-year college course will be an outstanding asset to add to one's résumé. Even so, being able to take courses and assimilate new information into life and work can also make a significant difference.⁴⁰ Adding new skills to one's knowledge base, identifying new interests, hobbies, and avocations, and making new friends are all mediated in a very effective way through postsecondary education and life-long learning experiences. For those students with ASD for whom postsecondary education is an option, inclusion of such experiences for the purposes of a diploma or for personal growth and development is a final important ingredient in an exemplary transition program.

The authors propose that these elements are essential to ensuring a successful transition from school to work for individuals with ASD. The next section reviews the employment supports that further the success of young adults with ASD in their quest for a full and connected life.

EMPLOYMENT MODELS FOR INDIVIDUALS WITH ASD

As noted earlier, individuals with ASD can work with proper supports. In fact there is a growing literature suggesting that individuals with ASD achieve many desirable outcomes when they are able to work independently in a community-based environment.²¹ Even so, individuals with ASD may require support to achieve these outcomes. This section describes supported employment for individuals with ASD and reviews some specialized vocational models that are reporting preliminary success.

Supported employment is an approach that helps individuals with ASD acquire, learn, and maintain competitive employment in a regular job for a competitive wage. Wehman and colleagues²⁹ described such a program whereby individuals with ASD achieved and maintained employment in a suburban hospital in a variety of paraprofessional positions at a competitive wage. The Federal Register defines supported employment as "competitive employment in an integrated setting with ongoing support services for individuals with the most severe disabilities" (Federal Regulations Register, 2002). **Table 2** displays the 4 major components required for implementing a supported employment program.

Supported employment is arguably the single most influential practice that results in employment for youth with ASD. Incorporating this support, there are other emerging models of employment that are resulting in employment in "real jobs" for individuals with ASD: business partnerships, customized employment, and self-employment. Each is described here.

Business Partnerships

Individuals with ASD have tremendous personal strengths that make them excellent employees. For example, the insistence on a consistent routine, attention to details, and general preference for visual order make adults with ASD successful employees at particular kinds of tasks. Although individual differences may exist, many adults with ASD display some or all of the characteristics listed in **Box 1**.

Because of these strengths, many businesses are collaborating with disability-specific employment organizations to increase the employment of individuals with disabilities. Examples of these employment partnerships result in "real jobs for real pay" for individuals with ASD and other disabilities. The partnerships are successful

Table 2 Four components for implementation of a supported employment program		
Component	Description for Individual with ASD	
Job-Seeker Profile and Assessment	Collect information about the person's strengths, interests, needs, and previous experiences. Develop a clear picture of the job seeker's skills and needs	
Job Development and Career Search	Finding and matching job requirements, employment, social, and communication environment, and job seeker. This step is critical to the success of the person's work life. Persons with ASD are particularly affected by subtle aspects of an employment environment that can lead to success or cause the person to leave the job early	
Job-Site Training and Support	Once on the job, a job coach will teach the person every aspect of the job from the necessary social "soft" skills to the job requirements. This step frequently requires the implementation of visual supports, applied behavior analytical teaching strategies, and the use of adaptive aids such as the iPod Touch to increase independence at work	
Long-Term Support and Job Retention	Continuing to follow individual with ASD through changes in work and job assignments and to provide additional training as needed	

Box 1

Strengths observed in workers with ASD

- Attends regularly due to resistance to changes in routine
- Demonstrates high rate of accuracy once task is learned
- Attends to small details and can become adept at self-correction
- Prefers visually organized environments and will bring order to disorganized environments
- Displays excellent memory for details
- Enjoys completing tasks
- Prefers work over socialization
- May have detailed information in area of special interest

in Walgreens, Bank of America, Marriot Bridges and, most notably, Cincinnati Children's Hospital Project SEARCH, which has been replicated internationally at numerous sites. 1,41,42 In this model, supported employment is used to support workers in these specialized businesses until the employee is independent. One specialized demonstration of this model for individuals with ASD has resulted in graduating adults with ASD acquiring employment at a suburban hospital. 43

Customized Employment

Customized employment is a model that allows a person with ASD to negotiate a personalized job independently or through a job negotiator. The job coach frequently acts as the job negotiator. ⁴⁴ In one example of this model, a job coach met with the owner of a small coffee and sandwich shop in a college town to negotiate a job for a person with ASD. In this example, the job coach arranged for the individual to prepare vegetables for sandwiches, stock the drink cooler, and deliver orders within a 4-block radius of the store. These tasks did not comprise the typical job in this establishment, but did serve the needs of the business and the employment needs of this individual with ASD.

Self-Employment

In this model of supported employment, individuals with ASD have the opportunity to develop a community-based or home-based business that capitalizes on their personal strengths. ⁴⁵ Due to personal circumstances such as challenging behavior or intensity of support needs, individuals with ASD can develop their own business whereby they can define their job and the time they will devote to that job. Perhaps one of the most notable examples of this model is Poppin Joe's Kettle Korn in Louisburg, Kansas (see: http://www.poppinjoes.com/home). ^{46,47} Joe is a young man with ASD. With support from his family members, Joe now owns and operates a very successful kettle popcorn business. He specializes in popping and selling a variety of different-flavored popcorn.

As noted earlier, Darius' family asked the family physician what Darius' future held. Would he be able to work, live independently, have friends, and even have a girlfriend? If he is provided with an excellent transition program that results in employment and other desired outcomes, the answer is a resounding yes. In fact, when provided with the proper educational and work supports, adults with ASD are living full and connected lives and are working in their communities.

IMPLICATIONS FOR HEALTH PROFESSIONALS

The transition issues faced by youth with ASD have serious implications in communication with and planning by health professionals. Like Darius and his family, most of these students and their families will have the following questions:

- Can I go to college?
- Will I be able to work?
- Should I plan on my child living with me forever?
- How does our family manage behavioral and psychiatric problems that are presented by my child?
- How do we manage issues related to sleeping, restlessness, and other somatic issues?

For health professionals such as physicians and school psychologists to answer these questions, it is important to be knowledgable about the vocational, social, and postsecondary capacity that many of these students may demonstrate. More importantly, however, health professionals should recognize the tremendous capacity that students with ASD have to become fully contributing members of their communities.

It is a fact that many of these students will participate in school programs that do not enhance these positive outcomes, because of curriculum and instruction that does not reflect best practices. Nevertheless, as the authors have suggested, the potential of these students is quite substantive when given the proper training and support.

Physicians, especially pediatricians and experts in adolescent medicine, must be aware of the impact that excellent transition programs, evidence-based strategies, supported employment, and specialized employment models can have for students with ASD. Likewise, school psychologists must be highly sensitive to what teachers and families are doing to help these students. Finally, all health professionals who serve individuals with ASD must communicate the tremendous outcomes that can be achieved for individuals with ASD when they receive meaningful educational interventions across their entire school careers. With new advances in providing support and teaching, individuals with ASD are achieving successful outcomes and increasing their quality of life.

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