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# Autism in the Workplace: Assessing the Transition Needs of Young Adults with Autism Spectrum Disorder

## **Comments**

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# Autism in the Workplace: Assessing the Transition Needs of Young Adults with Autism Spectrum Disorder<sup>1</sup>

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*Over the next decade, close to half a million people with Autism Spectrum Disorder (ASD) will reach adulthood. Research suggests that the career and life outcomes for young adults with ASD are poor as compared with those of the general population. Nevertheless, there is relatively little research on the work experiences of young adults with ASD that focuses on their career aspirations, preparation for work, career experiences, and the barriers associated with their transition into the world of work. Given the large numbers of young adults with ASD who are exiting secondary school and vocational training programs, it is imperative to understand the issues associated with their transition into the world of work. The purpose of this study, which utilizes a survey questionnaire and focus group, is to assess the transition needs and experiences of young adults with ASD as they prepare to enter the workplace. The results indicate that young adults with ASD face significant transition barriers when navigating the world of work and have certain transition needs. Policy implications for the transition needs identified are presented.*

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According to Autism Speaks (2016), “Autism spectrum disorder (ASD and autism are both general terms for a group of complex disorders of brain development. These disorders are characterized, in varying degrees, by difficulties in social interaction, verbal and nonverbal communication and repetitive behaviors.” The World Health Organization (2013) describes ASD as “neurodevelopmental impairments in communication and social interaction and unusual ways of perceiving and processing information” (p. 7). As such, individuals with ASD often have difficulty in understanding the thoughts, intentions, and emotions of others (Bruggink et al., 2016) and in regulating their own emotions. These challenges may create transition and employment issues for young adults with ASD (Samson, Huber, & Gross, 2012).

According to the Centers for Disease Control and Prevention (CDC, 2016), 1 in 68 children are on the autism spectrum and the presence of ASD is four to five times more common in boys (1 in 42) than in girls (1 in 189). The number of people affected by ASD is estimated to be in the tens of millions worldwide, with 3.5 million in the United States (Autism Speaks, 2016). Further, over the next decade, close to a half-million people with ASD will reach adulthood (CDC, 2016), and it is estimated that 70% of these young adults will be unable to live independently (National Autistic Society, 2016).

Currently, the cost of autism services in the U.S. exceeds \$236 billion annually (Buescher et al., 2014), and this number is expected to rise to \$1 trillion by 2025 (Leigh & Du, 2015). Supporting an individual with ASD may exceed \$2 million over his or her lifetime (Buescher et al., 2014). In addition, indirect costs, which are more difficult to measure, are expected to increase and include lost income and career opportunities due to movement in and out of the labor force by the individual with ASD as well as the cost of lost productivity by the individual with ASD and his or her parents.

The most recent unemployment statistics for adults with ASD show that 85% are unemployed and that 69% of them want to work (National Autistic Society, 2016). The cost of these adults not working contributes to the financial toll on their families and society. Even when individuals with ASD do work, employment outcomes for adults with ASD have been found to be lower than those for the general population (Jennes-Coussens, Magill-Evans, & Koning, 2006; Taylor, Henninger, & Mailick, 2015).

Further, research suggests that those individuals with ASD who secure employment face significant challenges in maintaining employment (Baldwin, Costley, & Warren, 2014; Lorenz & Heinitz, 2014; Richards, 2012; Roux et al., 2013), and, as noted, it is likely that their career path may involve multiple movements in and out of the labor market. Nevertheless, there is little research on the emotional and psychological effects of multiple job losses and repeated movement in and out of the labor market on individuals with ASD and their families.

Finally, quality of life outcomes for young adults with ASD have been found to be lower than those of the general population. Taylor and Seltzer (2011) found that these young adults are three times more likely to have no daytime activities compared to individuals with other disabilities (Taylor & Seltzer, 2011). In addition, a survey of 200 families of adults with ASD found that 85% still lived with their parents, siblings, or older relatives (Gerhardt & Lanier, 2011). Employment is a critical component for adults with ASD to become engaged members of society and to lead lives of quality and dignity.

A primary concern for parents is whether their children with ASD will be able to live independently as well as be fully employed and able to support themselves financially.

Easter Seals (2008) surveyed over 2,500 parents of children with and without ASD. The results indicated that quality of life was a much larger concern for parents of children with ASD than for parents of children without ASD. The parents of children with ASD were significantly more concerned about what would happen to their children when they (the parents) die, and many of their fears were financial. Parents of children with ASD were worried that the cost of caring for someone with ASD would drain the family's finances and be detrimental to the financial future of the other siblings. Of the parents of children with ASD, 61% reported having to incur debt to meet their family's needs, as compared to 46% of parents of children without ASD.

As noted, little is known about the career experiences of young adults with ASD (Johnson & Joshi, 2016). In particular, it is very difficult to track individuals with ASD once they leave high school as there is little coordination among the agencies that provide transition services to assist these young adults and their families with career planning (Pellicano, Dinsmore, & Charman, 2014). Young adults with ASD are protected by the Individuals with Disabilities Education Act (IDEA), a federal law that calls for the provision of services to children with disabilities until the age of 22 or when they graduate from high school (U.S. Department of Education, 2004). Services provided under this law enable young adults to be placed in work situations or to participate in work programs through their school districts. There is great concern about the lack of services available for young adults with ASD because once they reach the age of 22 they are no longer protected by IDEA (Roux, 2015). Roux refers to this as the *services cliff* and states that there is an urgent need to create effective transition planning and programming for these young adults.

The transition process, with its new tasks and experiences, may be particularly challenging for young adults with ASD. Many will lose the services provided by their school districts just as they begin to enroll in post-secondary education programs or enter the work force. Further, most will continue to need some type of support to reach their educational, career, and life goals.

In addition to creating transition planning and programming, there is an urgent need to identify the transition needs of young adults with ASD and the barriers that they may encounter. It is important to understand transition needs, specifically from the perspective of the young adult with ASD as well as from the perspective of parents and caregivers. Anecdotal evidence of the barriers faced by young adults with ASD may be found on the websites of several nonprofit organizations and autism support groups (e.g., [autism.org.uk](http://autism.org.uk); [hloom.com](http://hloom.com); [sunderland4autism.com](http://sunderland4autism.com)). The need for support and services for these young adults while navigating the employment world is a consistent theme identified by parents, caregivers, and young adults with ASD.

A comprehensive study of the transition from high school to early adulthood was conducted by the National Center for Special Education Research (NCSER, 2007). The National Longitudinal Transition Study 2 (NLTS2) concerned the educational, vocational, social, and personal experiences of students in special education programs as they made the transition from high school to early adulthood. It should be noted, however, that the focus was on young adults with disabilities in general and not the

transition needs specific to young adults with ASD. The key results indicated that secondary school students with ASD take a range of courses, including academic, vocational, and life skills. Virtually all secondary students with ASD take at least one non-vocational special education course during a semester; have some type of accommodation, modification, support, or technology aid; and receive a variety of related services for various needs and functional issues.

Additional findings from the NLTS2 study indicated that some young adults with disabilities plan to attend a two- or four-year college or to enroll in postsecondary vocational training. The study also indicated that their transition goals include gaining competitive, supported, or sheltered employment. Moreover, the results showed that living independently is a transition goal for most students with disabilities and that some students were working toward maximizing their functional independence or enhancing their social or interpersonal relationships. These results suggest that students with disabilities have a need for transition services, including accommodations to help in their pursuit of educational goals as well as vocational services such as vocational training, job placement, or support services to help them to identify and secure employment as well as to live independently (NCSE, 2007).

Therefore, the purpose of the current study is to explore the career experiences of young adults with ASD with a focus on their career aspirations, preparation for work, and career experiences, as well as the barriers associated with their transition into the world of work. Specifically, the study sought to identify the transition needs of young adults with ASD using both a survey questionnaire and a focus group. A review of the literature in each of these areas is presented in the following section.

## Review of the Literature

### *Career Aspirations*

Although much is known about the early career stages of young adults, research suggests that adults with disabilities have career paths that differ from those of the mainstream populations that have been commonly studied in the management literature (Heslin, Bell, & Fletcher, 2012; Zikic & Hall, 2009). Further, very little is known about the career stages and experiences of young adults with ASD, including their career aspirations, career exploration activities, the school-to-work transition, the job-search-and-choice process, actual work experiences, and the associated transition needs for support and services throughout these stages.

Super (1957, 1980) suggests that that our occupational choices are how we define ourselves and actualize our self-concept. Super's model of career development, particularly the growth and exploration stages, has been used to understand how adolescents and young adults develop into members of the workforce. Super believes that individuals develop their self-concept and ideas about the world of work during the growth stage (birth to age 14), which is followed by the exploration stage, during which the young adult (ages 15–24) "tries out" different occupations through classes, hobbies, and work experiences. These experiences help the individual to refine his or her conception of different occupations and to assess whether these would be a good fit with his or her skills and preferences. Very little is known, however, about

the exploration stage of career development for young adults with ASD, particularly with regard to their career aspirations, knowledge of the skills, education, and training needed to pursue specific occupations, and a general understanding of the world of work.

### *Preparation for Work*

Typical activities in the preparation-for-work stage include obtaining relevant education and training; participating in internships, hobbies, and other paid and unpaid work; and preparing for the job-search-and-choice process by researching employment opportunities, preparing one's resume, and practicing for interviews. It is difficult, however, to track the preparation for work activities of young adults with ASD, and there is very little research on the job-search process of young adults with ASD (Paul, Laird, & Tune, 2016). The limited research available has found that 59% of young adults with ASD, aged 16 years or older, have not yet looked for work, while 75% of their same-age peers are already working (Easter Seals, 2008). Other research suggests that many young adults with ASD have difficulty finding jobs, completing post-secondary courses, and supporting themselves to live independently after high school (Gerhardt & Lainer, 2011). In addition, young adults with ASD are less likely to use their social connections to find a job (Baldwin et al., 2014). Contributing to the difficulty of finding a job, adults with ASD have been shown to have low self-efficacy in terms of their belief that they can work (Lorenz, 2016; Lorenz & Heinitz, 2014), and this belief may be reinforced if they have negative work experiences (Heslin et al., 2012). Finally, efficacy beliefs are highly related to occupational choice (Bandura et al., 2001).

Some studies have considered the variables that affect the ability of an adult with ASD to be employed. One study found that annual household income, social skills, parents' education, graduation from high school, receiving career counseling during high school, and having the school maintain contact during post-secondary training programs are all significantly positively associated with a young adult with ASD's ability to be employed (Chiang et al., 2013). Another study found that high school employment experiences and high parental expectations of post-high school employment were the strongest predictors of employment of young adults with ASD (Wehman et al., 2015).

To achieve these outcomes, young adults with ASD need to have a transition plan and access to transition services. Transition services are a "coordinated set of activities" for youth with special needs that are intended to focus on improving vocational and functional skills (U.S. Department of Education, 2004). These activities should facilitate successful movement to greater levels of independence, including transitioning to post-secondary education, vocational training, employment opportunities, independent living, and positive community participation. The transition-planning-and-intervention process often includes assessment, skills instruction, and community-based experiences. There are few programs available, however, that focus on these youths (and their parents) having meaningful involvement in the employment process.

### *Career Experiences*

Adults with ASD may typically have more difficult career experiences than those of their peers. Studies of young adults with ASD found that these individuals have much higher rates of unemployment than the general population (Baldwin et al., 2014; Krieger et al., 2012; Nord et al., 2016; Richards, 2012; Roux et al., 2013; Scott et al., 2015; Shattuck et al., 2011). Estimates of the unemployment rate for individuals with ASD are mixed, but research has shown that many individuals with ASD have never been members of the labor force (Cidav, Marcus, & Mandell, 2012). Shattuck et al. (2012) found that 35% of young adults with ASD have never held a job or attended post-secondary education. The National Autism Society (2016) estimated the unemployment rate to be as high as 85%, while a study of 200 transition-age young adults with ASD found that 81% were unemployed (Gerhardt & Lanier, 2011). A small study of young adults with ASD and IQs above 50 found that only 11.76% were employed (Howlin et al., 2004). One study showed that approximately half of young adults with ASD worked for pay after high school (Roux et al., 2013). The same study also found that the odds of ever having a paid job were higher for those who were older, from higher income households, or who had better conversational or functional skills (Roux et al., 2013).

What might account for the differences in unemployment rates reported for adults with ASD? One explanation is that the variance may be due to differences in the populations sampled. Another explanation is that both full- and part-time employment are often included when calculating unemployment rates. In addition, individuals with ASD are often given fewer hours of work than they would like. One study found that 74% of young adults with ASD who worked were doing so only on a part-time basis (Gerhardt & Lanier, 2011). Baldwin et al. (2014) found that adults with Asperger's Syndrome, as compared to the general population, were more likely to work part-time. Finally, adults with ASD tend to be underpaid compared to their peers without ASD (Ballaban-Gil et al., 1996; Howlin et al., 2004; Roux et al., 2013).

It also is important to take into account the type of work included in the definition of employment. One study found that 56% of the individuals considered employed were working in day programs or sheltered workshops (Taylor & Seltzer, 2011). Howlin et al. (2004) found that 12% of individuals with ASD worked in supported, sheltered, or volunteer employment and that 62.5% were in some type of day program. Research also has shown that young adults with ASD are more likely to be overeducated and overqualified for their jobs, meaning that the work that they do is beneath their capabilities (Baldwin et al., 2014). Further, they work in a limited number of occupations (Roux et al., 2013). Finally, they are more likely to be underemployed (Baldwin et al., 2014; Krieger et al., 2012; Nord et al., 2016; Paul et al., 2016; Richards, 2012; Roux et al., 2013; Scott et al., 2015; Shattuck et al., 2011).

Adults with ASD also face significant challenges in maintaining employment (Baldwin et al., 2014; Lorenz & Heinitz, 2014; Richards, 2012; Roux et al., 2013). When they experience conflict or stress at work, adults with ASD may quit or miss work without prior notice (Richards, 2012). They also are more likely than their peers without ASD to change jobs frequently and, as a result, to experience higher levels of ongoing stress and financial concerns (Baldwin et al., 2014).

### *Transition Barriers*

During the transition process, young adults with ASD face transition barriers that are not seen among the general population (Seitz & Smith, 2016). One such barrier is the lack of coordination between the agencies that support young adults with ASD. For these young adults to be employed and contribute positively to society, these agencies need to collaborate. Further, although there are organizations that focus on the school-to-work transition of young adults with ASD, little is known about quality and impact of the services received. Another barrier is that many parents do not have the necessary information to navigate the transition process. One study found that, among families surveyed, 67% had no knowledge of available transition programs, 83% relied on family members as their primary source of transition planning assistance, and 78% were unfamiliar with agencies or professionals that might assist with job placement (Gerhardt & Lanier, 2011). A third barrier is the absence of qualified staff to work with young adults during transition (NYCA, 2012).

## **Purpose of the Study**

Research suggests that young adults with ASD experience significant difficulty in transitioning to work, but little research has examined the transition barriers and transition needs from the perspective of young adults with ASD or their parents and caregivers. Thus, the purpose of this study is to assess the transition needs and experiences of young adults with ASD as they prepare to enter the workplace. This study focuses on the current state of employment of youth with ASD while identifying the availability of services which are required to support improved employment outcomes, along with associated gaps in those services. Data were collected on career aspirations, preparation for work, career experiences, and transition barriers, as experienced by young adults with ASD. To this end, a methodology was used that included a survey questionnaire and focus group.

## **Method**

### *Survey*

The survey instrument used to assess the transition barriers encountered during this process was designed using the theoretical framework of the three-step career process of career aspirations, preparation for work, and career experiences. The instrument consisted of 37 questions, derived from a review of the literature. The number of questions offered to each respondent varied based on his or her characteristics. For example, if a respondent identified him or herself as a parent, the respondent was presented with slightly different questions than if he or she identified him or herself as a person with a disability. Standard automatic branch logic was used to allow for consistency among respondent groups. Based on the results of a pilot study of 18 individuals, stratified to the targeted respondent groups, the average time to complete the survey was 20 minutes. Face validity of the survey questionnaire was improved through a systematic feedback review of the instrument by administrators from local service provider agencies and parent support groups. The survey was administered in English and Spanish.

After obtaining IRB approval, the survey instrument was converted into the electronic survey platform Qualtrics for which a unique resource locator (URL) was created. Quantitative and qualitative data were collected. Quantitative data were obtained primarily through forced-choice or ranking questions, and an “other” or short text box was available for certain questions so that respondents could provide a more detailed response. The survey questionnaire cover letter assured respondents that their responses would be anonymous. The anonymous nature of the survey, however, precluded any follow-up by the investigators.

**Survey sample.** The county regional center, two local parent/caregiver support groups, and a community mental health service agency that support transition-aged youth, agreed to participate in this project. Each agency and group agreed to send to individuals on their proprietary lists an email invitation that contained a URL and an invitation to participate in the study. The survey was sent to the caregivers or family members of individuals with ASD. Young adults with ASD were also eligible to complete the survey. The survey link was active and open for 12 weeks. Participants were able to direct any questions or concerns to the authors and were fully informed, in the survey cover letter, that, by doing so, their identity would be revealed. The authors received no questions on how to complete the survey instrument.

Because the survey research methodology used an anonymous analytical process, the researchers had no knowledge of who responded; thus, only the demographic categories that the respondents provided were used in the study results. The survey cover letter contained information on the purpose of the study, the researchers and their affiliations, and the lack of risk associated with participation. The letter also stipulated that proceeding with the survey constituted consent to participate. Respondents were able to skip any question or exit the survey at any time.

A total of 200 respondents completed the survey. Of those respondents, 182 self-identified as caregivers and 18 as young adults with ASD. The responses from the 18 young adults were not included in these results due to the small sample size. Nearly 80% of survey respondents ( $n = 144$ ) identified themselves as mothers. The majority of participants identified as White (76%), followed by Hispanic or Latino (19%). Caregivers were defined as the parent, grandparent, sibling, relative, or other primary caregiver of a young adult with ASD. Of the young adults with ASD, 50% were between the ages of 15 and 20, 37% were between the ages of 21 and 25, and 14% were between the ages of 26 and 30. In addition, 82% were male.

**Generalizability.** Although the total respondent group comprised only 200 individuals, the composition of the group was generally comparative to that of the U.S. population within the targeted demographic categories. The sample's percentage of Hispanic or Latino participants (19%) compared to the national rate of 18%, and the proportion of respondents who identified as White (76%) compared to 62% nationally (U.S. Census Bureau, 2015). The main variation was the very low proportion of individuals who self-identified as Black, at 1%, as compared to 12% nationally. It should be noted that these variances are commonly seen in ASD prevalence studies, as an ASD diagnosis is much more prevalent among those who identify as White and least prevalent among those who identify as African American or Black (Mandell et al., 2007; Tek & Landa, 2012). The reported racial disparities in ASD identification among

minority children are troubling; nevertheless, the survey sample demographics were consistent with national population norms for ASD.

**Focus group.** A focus group was conducted with the caregivers of young adults with ASD. The topic of the focus groups was the career experiences of young adults with ASD. Participants were introduced to the general topic to be discussed and were asked for their experiences with the transition process. Although participants were prompted to elaborate on their responses, the format was generally conversational and informal to help families to feel comfortable and to elicit honest responses.

The focus group was conducted at a caregiver support group-hosted social event for young adults with ASD. The support group holds such events four times a year and draws a large group of young adults with ASD and their caregivers. The caregivers are encouraged to spend time with other caregivers while the young adults participate in supervised social interactions with their peers. This group was chosen based on the large number of participants that it draws, the private space provided for caregivers whose young adults are attending the event, and the range of young adults who attend (in terms of general ability levels and support needs).

**Focus group sample.** Approximately 35 caregivers participated in the focus group. Although all participants were encouraged to share their experiences, some contributed more or responded to the prompts more frequently than did others. All responses were recorded. During introductions, parents informally provided their background and some basic demographic data. Based on the information provided, we determined that the majority of participants were mothers of young adults with ASD. Approximately 15% were fathers, and approximately 5% were other relatives (e.g., aunts, grandparents, adult siblings).

## Results

Data from the survey and the focus group provided insight into caregivers' perceptions of the status of employment and employment services for people with ASD, the specific skill areas that require additional intervention, and services and supports that are still needed. These issues are discussed from the perspective of what hinders and facilitates improved employment outcomes for youth with ASD, specifically career aspirations, preparation for work, career experiences, and transition barriers that interrupt the career development process.

### *Career Aspirations*

The survey results indicated that 40% of the young adults did not show any interest in pursuing a specific job or career at some point in their lives. The caregivers of young adults with career goals stated that many of these young adults did not have realistic goals. Specifically, 65% reported that these goals were "not at all realistic or "slightly realistic." When caregivers were asked whether the young adult appeared to have a realistic view of the world of work, 61% reported that the young adults had a "not at all realistic" or "slightly realistic" view. When asked whether the young adult understood the education and training required to pursue a career, 72% of the caregivers reported that they had "no understanding" to "some understanding" and

that only 27% understood most or all of the requirements.

During the focus group, many of the caregivers reiterated these concerns. They felt that the young adults did not have realistic career goals or a realistic sense of work because they were not provided with the opportunities needed to understand their options, explore potential work environments, or gain hands-on experience. Not only did parents feel that their children were not having the same conversations about their future careers and opportunities as were their peers in school, they also felt they needed a different approach to learning about the world of work.

Participants stated that people with ASD typically “learn by doing.” Specifically, these young adults need to be taught skills in the environment in which they will use them and often need to be exposed to actual experiences as a means of visualizing or understanding what work might be like and how they might fit into the work of world. Parents discussed what they felt was needed to adequately train and prepare their children for employment, including volunteering, job shadowing, and working with support and supervision, which are discussed below.

### *Preparation for Work*

Preparation for work ideally occurs across the lifespan in various skill areas. Caregivers who completed the survey questionnaire noted that the services most needed to prepare young adults for work including help in finding a job, training in specific job skills, and training in the life skills needed for work. Preparation for work occurs over many years across multiple settings (e.g., schools, communities, colleges). With regard to early preparation, the survey results indicated that many of the young adults participated in extracurricular activities in the community (84%). In addition, approximately 40% had volunteered in some capacity, with over 45% who had served as volunteers for over three years.

During the focus group, participants indicated that they often tried to involve their child in community activities and that this required a lot of time and dedication. Caregivers noted that participating in community programs was more difficult for some young adults due to certain problem behaviors that interfere with their ability to safely interact with others. A few participants stated that volunteering had been helpful for their young adult to develop necessary employment skills and to create potential job opportunities. Parents felt that early preparation in life skills and academic skills was essential but also noted that this was significantly lacking in their communities. Parents reported a desire for training and skill-building opportunities to occur much earlier than high school and certainly before the youth completed his or her high school program.

Of those who finished high school, 80% had participated or continued to participate in some form of post-secondary education or training. Approximately 54% were in community college, 13% in a four-year college, 13% in a specialized college for students with disabilities, and 7% in a vocational training program. In addition, 13% indicated they participated in some other post-secondary education opportunity. Although it is promising to see that many young adults continued their education or training after high school, the results indicated that only 13% had completed their programs, 51% were still attending, and 25% did not complete the program. Caregivers reported that 26% of the young adults were in a job-related training program and that 45% were paid while in the program.

Responses in the focus group echoed those for the survey questionnaire. Many caregivers reported that their young adult was attending community college, with a few in other programs such as vocational school or specialized colleges. Caregivers reported that vocational programs were often expensive and not financially sustainable for the family. Many chose the community college setting due to the variety of options in terms of education and training, as well as the cost. Of those in community college, some were in certificate programs, while others were working toward completing an associate's degree at a slower than typical pace.

The majority of the parents stated that their young adult was struggling to be successful in post-secondary education settings. They felt that these struggles were due to a lack of the general life skills required to be successful in an academic setting (e.g., social skills, planning/organization skills) or a deficiency in the academic skills required. The caregivers further stated that, generally, there was not enough support provided for youth to be successful in these community college programs, unless the program was developed specifically for youth with disabilities. Many young adults with ASD are accustomed to an adequate level of services and support while participating in school district programs, and much of this support is no longer available once they complete high school and attend post-secondary education programs. Those who have made some progress in these settings attribute that development to supportive teachers or staff members, rather than to the education system being set up to support success.

The job search is the final step in moving toward the world of work and typically transpires after some early preparation has occurred. The survey data indicated that, of those working, approximately 58% had found their job through a support agency such as a regional center, the department of rehabilitation, or their school district. In addition, close to 23% found work through personal relationships, such as family or friends. Focus group participants explained that finding jobs for their young adults was extremely challenging and felt that, unless they created the opportunities themselves through their personal connections, the opportunities were extremely limited.

Of the young adults who were unemployed, over half (53%) had not used any approaches (e.g., networking with family or friends, responding to job listings or advertisements) or available services to find employment in the previous six months. In addition, caregivers who completed the survey reported a lack of interviewing skills, which significantly hinders one's ability to obtain employment. This was echoed by the focus group participants, who also indicated that, after multiple failed attempts at obtaining employment, many of their young adults had "given up" and were unable or unwilling to continue to experience this form of rejection.

### *Career Experiences*

To enhance outcomes for young adults with ASD, it is crucial to understand the experiences of those who have been or continue to be employed. Of the survey participants, 36% worked at some point. Specifically, 89% had held one to three jobs, and 75% had worked more than a year. Approximately 22% of all participants were currently working for pay. Of these, 43% were working part-time and indicated that they would like to work more hours. In addition, 88% of those who were working were earning minimum wage or higher. Nevertheless, 65% of those who were working did

not receive any benefits (e.g., sick pay, holidays, retirement).

When asked on the survey questionnaire about the most challenging issue that young adults face, respondents indicated that finding employment that allows for financial independence was the number one concern. This finding was consistent with the focus group data. Focus group participants clearly communicated that, as a community, they needed to have jobs available to young adults with ASD that provide a “livable wage” and benefits. This was particularly important because many of these young adults have additional medical and mental health complications that may not be adequately covered by government-subsidized insurance programs.

The second most challenging area for families was “finding a work environment that is supportive of a person with a disability.” Despite the widely shared perception of inadequate acceptance and support, those who were working did report some level of support. Of these participants, 68% reported that a support agency had stayed in touch with them to check on their job progress, and 50% reported that they had received some accommodations or services from their employer due to their disability. Among the young adults with ASD, 66% indicated to their caregiver that they like their job very much. Focus group participants stated that, when their young adult is able to work in an environment in which their passions, interests, and skills match the needs of the job, they are much more successful. Participants were concerned, however, that many support programs and related job opportunities were not matched to their young adult’s skill set. They noted that some youths were put in positions that directly conflicted with their skills and interests (e.g., placing a person who struggles with social communication in a customer service position).

### *Transition Barriers*

Although all young adults face obstacles as they move through the career development process, young adults with ASD face multiple barriers that are particularly detrimental to their career progress. These barriers include mental health issues and other co-occurring conditions, a significant decrease in services following high school completion, and a lack of communication and collaboration across stakeholders and settings.

The survey data indicated that ASD co-occurred with other diagnoses (not including strictly medical conditions) in 82% of cases. The most frequently co-occurring disorders were mental health-related, such as depression or anxiety. Participants in the focus group discussed the impact of these mental health challenges on employment. They talked about their young adults’ experiences with depression related to multiple experiences of “failure” throughout their academic careers, in their social experiences, and, now, in their adult lives. These multiple experiences of failure often lead these young adults to “shut down” and no longer want to try or put themselves in a position for future rejection, which ultimately leads to a loss of motivation to obtain employment. They also talked about how overwhelming it was for young adults with ASD to not know or understand what their future would be like and that many of these young adults feel anxious about what the world of work is like. The caregivers reported that many young adults avoid seeking out job opportunities or engaging in activities that they feel may overwhelm them or lead to failure. This avoidance could lead to a reduced likelihood of obtaining and maintaining meaningful work.

Related to these mental health challenges is the reduction in services that occur after high school completion. Although many students receive mental health services in school, the survey data showed a significant (50%) decline in this type of support after high school. Not only were mental health services reduced but other services that are critical for employment success were as well. For example, the survey data indicated an 83% decline in speech and language services post-high school. Further, a great deal of supervision and oversight, which is typically provided during high school, declined following completion of high school. Focus group participants stated that, if there were no supervision, they would have major concerns about their young adult's participating in the workforce in terms of safety issues. Parents reported being concerned that their young adult may not recognize dangerous situations in the workplace or in the community on the way to work. They worried that the young adults may be taken advantage of at work because they are naïve and that, if an incident does occur, they may not respond appropriately to authorities or be able to accurately report the incident due to their disability.

In addition to the steep reduction in services, there is a lack of communication and coordination across agencies and stakeholders. With regard to the employment of youth with disabilities, stakeholders can include the young adult, caregivers, school districts, and services providers as well as employers. Focus group participants reported, however, that they received most of their information about available training and job opportunities by word of mouth from other parents or by searching the internet. Information was not typically obtained by speaking with service providers or employers, which, participants felt, led to inconsistent, nonexistent, or inappropriate services. Parents also discussed the lack of communication across stakeholders, noting, "It feels like no one is talking to each other," as well as their expectation that they needed to serve as case managers to hold all of the pieces together. When there is little communication and sharing of data, services are less effective and the potential for positive employment outcomes is reduced. Participants suggested that a streamlined approach to employment communication would allow for more effective services and for a more comprehensive understanding of the appropriate steps to take toward meaningful employment.

## Discussion and Recommendations

The results of this study indicate that young adults with ASD face significant challenges when navigating the world of work. Not only is it important that these young adults find a job to obtain financial support, security, and independence but also to secure their quality of life, sense of safety, and belonging in the community. To that end, the data revealed significant needs in terms of career aspirations, preparation for work, and career experiences as well as barriers to successful transition into the world of work. Based on the needs identified in the study, recommendations for intervention and policy also are provided.

### *Career Aspirations*

It is clear that schools and parents must work together to assist young adults with

ASD to develop and explore realistic career aspirations. The concerned parties may begin this process by implementing a number of tasks early on in the child's development. These tasks can include early training in the life skills required to be a successful working adult, creating a curriculum focused on career options for youth with disabilities, having discussions about career options and pathways, and developing partnerships with employers to create hands-on career experiences and training programs.

### *Preparation for Work*

The results indicate that preparation for work should occur over many years across multiple settings (e.g., schools, colleges, communities, businesses). Preparation should focus on key areas such as training in specific job skills, training in life skills needed for work, and preparing the young adult to find a job. Although there are a number of evidence-based interventions available to help guide job skill development (Test et al., 2009), few providers are able to implement them as designed. Thus, it is important to develop policies and practices to create incentives to hire, train, and maintain staff with expertise in using these interventions with young adults across all settings. As noted, training in the life skills needed for work can occur in multiple settings and involve multiple stakeholders, and these training opportunities should focus on community involvement and volunteer participation to assist in generalization of work skills. Finally, these young adults will need skilled help in securing a job, including help in applying for jobs and interviewing skills.

### *Career Experiences*

To create an environment to facilitate career opportunities and successful career experiences for young adults with ASD, educators, counselors, and service providers must develop and implement evidenced-based practices that allow for the effective assessment and matching of interests and passions to available jobs. Further, in an effort to support employers who choose to invest in this population, employers should be trained in the benefits of hiring adults with disabilities (e.g., loyalty and reliability, work completion, rare technical skills, reputational benefit), including the financial benefits. In addition, policies that enhance incentives for businesses to employ people with disabilities are needed. Employers and other stakeholders must work together to develop effective programs that will benefit the employer, the young adult, and the community as a whole.

### *Transition Barriers*

There are multiple barriers to these young adults' smooth transition into the workplace. These include a lack of effective mental health services and problems with communication and collaboration across stakeholders, which, in turn, result in difficulties in the implementation of existing policies. Many of the difficulties related to youth's "giving up" on finding employment can be explained by mental health issues. Better mental health options need to be developed for youth with ASD who are making the transition into adulthood. Clinicians who can be appropriately trained in this specialized area need to be identified and supported, and better systems to enhance communication and collaboration across settings must be put in place.

Although there are many interventions available that focus on specific work skills, there do not appear to be evidence-based interventions that address interagency collaboration (Test et al., 2009). To have an effective collaboration process, existing evidence should be used to develop a formalized model of collaboration, and its effect on outcomes, studied. This model will assist in developing a bridge between specific policies and legislation that will guide adult services and the implementation of these policies in the community and workplace and, in turn, will help practitioners to complete ongoing developmental evaluations of the new programs to determine what works and to make adjustments as needed.

### *Limitations*

This study had several limitations. First, due to the anonymous nature of this survey, it is difficult to determine whether these participants are representative of the parents and caregivers of young adults with ASD in general. In future studies, investigators may gather more in-depth information about the participants in order better understand the representation of the sample. Second, all respondents had access to the internet and the time to complete the survey questionnaire. Therefore, this may not represent a cross-section of the potential people impacted by these issues, as respondents to online surveys may be more likely to be frequent users of computers and heavier users of the internet and email than non-respondents. In addition, families who support youth with ASD may have limited time to respond to such requests and perhaps only those who were able to find some respite were able to complete the survey. In order to address some of these concerns, investigators of future studies may consider utilizing different or varied approaches for gathering information. One recommendation for future research is to use in-depth interviews conducted across several years in order to track outcomes across development. Finally, it is possible that this sample was comprised primarily of participants who were highly motivated to complete the survey and provide feedback, perhaps because they were having exceptional difficulties with issues of employment and transition to increased independence. Future studies may consider using alternate survey methods and a random sample to control for the self-selection bias that occurs with online surveys.

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