



Young Adults on the Autism Spectrum and Early Employment-Related Experiences: Aspirations and Obstacles

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Abstract

In the United States, employment outcomes for young adults with an autism spectrum disorder (ASD) are poor, with many unemployed, underemployed, or otherwise unable to achieve their potential regardless of cognitive ability. To explore employment expectations and experiences, qualitative interviews were conducted with 12 young adults with ASD and 28 parents. Transcripts were analyzed using the constant comparative method associated with a grounded theory approach. Three major themes emerged: *Employment Aspirations and Potential*, *Challenges of Job Finding and Keeping*, and *Differing Parent and Young Adult Work-Related Roles and Views*. Issues discussed include the need to foster meaningful pre-employment opportunities, acknowledge the role of families in employment issues, provide ASD-focused workplace support, and effectively coordinate intersecting systems (e.g., schools, agencies, employers).

Keywords Adolescents · Autism spectrum disorders · Developmental disabilities · Employment · Qualitative research · Young adult outcomes

Introduction

For typical young adults, securing a full-time job is one of the markers of a successful transition into adulthood (Osgood et al. 2005). Employment contributes not only to financial independence but to psychological health, providing daily engagement, social connection, and self-esteem (Blustein 2008). Unfortunately, obtaining and maintaining employment is often a challenge for individuals with autism spectrum disorder (ASD), regardless of cognitive ability (Chen et al. 2015; Wilczynski et al. 2013). The limited available research does not fully explain why this is the case. This may be due in part to the complexity of issues surrounding employment for young adults with ASD, from the multiple intersecting organizations involved in employment for individuals with disabilities (McDonough and Revell 2010) to the heterogeneity of the autism spectrum itself (Hedley et al. 2017).

To transition a young person with ASD from the role of high school student to that of employee involves coordination across a number of systems, including schools, service-providing agencies, and employers (Gerhardt et al. 2014). Public high schools play a crucial part in this process, as mandated under the Individuals with Disabilities Education Act (IDEA 2012). They are obligated to help their special education students connect with adult service systems and either employment opportunities or postsecondary education (PSE). For example, they may point the way to the appropriate state developmental disability agency (and related agencies that actually run programs, such as the Arc or Easter Seals); a vocational rehabilitation (VR) agency that provides preparation for and links to employment; or postsecondary programs at community or 4-year colleges which it is hoped will likewise pave a path to employment. Regrettably, there is evidence that this mandate is not being carried out on a consistent basis for youth with ASD. Utilizing data from the National Longitudinal Transition Study (NLTS-2), which documents the experiences of U.S. teenagers moving from secondary school into adulthood, Shattuck et al. (2012) demonstrated that more than half of young people with ASD who had left high school in the past 2 years were neither employed nor attending college.

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Young adults with ASD fare worse in terms of employment even when compared to individuals with other types of disabilities. Roux et al. (2013), also using NLTS-2 data, discovered that adults ages 21–25 with ASD were less likely to have ever worked for pay and, if they were paid, had significantly lower wages than same-aged peers with other learning or developmental disabilities. A related study reported that young adults with ASD were not only the least likely group to be looking for a job or to have found a job on their own, but also took an average of 14 months to find a job—longer than any other disability group (Wei et al. 2018). Furthermore, disruptions in postsecondary vocational or educational path appear to be common. In a study of 36 youth with ASD, one half experienced such disruption in the 2–3 years after high school, and these were significant, including “job loss and expulsion from institutions of higher learning” (Taylor and DaWalt 2017, p. 4029).

What limited information exists on longer-term trends in employment is likewise discouraging. A “state of the states” report on employment outcomes of transition-aged adults with ASD declared that over a 10-year period (2002–2011) there had been no improvement in the percentage of adults on the autism spectrum obtaining employment. There had likewise been no improvement in mean number of hours worked or wages earned, both of which were low even in comparison to those of other VR clients (24 vs. 31 h per week and \$198 vs. \$297 per week, respectively) (Burgess and Cimera 2014). In addition, according to Roux et al. (2018), analysis of data from the U.S. Department of Education’s Rehabilitation Service Administration (RSA), which tracks VR statistics, revealed that employment outcomes for VR-receiving youth with ASD actually declined in most states across the same period. On a more encouraging note, VR outcomes were better in states where a larger percentage of youth with ASD were applying for VR services in high school, a possible indicator of transition preparedness and coordination between high schools and VR agencies.

Determining what underlies such negative outcomes is complicated by the heterogeneity of individuals with ASD in terms of numerous factors, including cognitive ability. This touches upon the sensitive issue of how to group and describe those on the autism spectrum. For the purposes of this paper, and consistent with our earlier work, we will utilize the terms “ASD with intellectual disability” (ASD-ID) and “ASD with typical cognitive ability” (ASD-CA). Though far from perfect, these are meant to capture intellectual ability only, and to be an improvement over ill-defined and deceptive terms such as “low-functioning” and “high-functioning.” As noted by Kenny et al. (2016), the former insinuates that those with ID are without strengths or capabilities, while the latter implies that higher IQ individuals with ASD face few challenges and need little support.

Neither is the case. Still, the usual path for those who are ASD-ID versus ASD-CA differs.

For example, students with ASD and intellectual disability (ASD-ID) generally remain in high school until age 21, receiving a certificate of completion rather than a diploma. These students are eligible for longer-term vocational support and may better fit the model and expectations of adult service-providing systems than students with ASD with typical cognitive ability (ASD-CA). Still, their families must fight to obtain appropriate services, including access to employment—a convoluted process made all the more difficult if an individual with ASD has any challenging behaviors such as elopement or aggression (Anderson and Butt 2018).

Further complicating assessment of outcomes of young adults with ASD-ID is the fact that possible employment settings for this group are so varied. These may include work taking place in a day program, supported employment (with the help of a job coach), and competitive employment in a typical workplace with or without support (Gerhardt et al. 2014). Fortunately, there has been a move away from sheltered workshops, with their legacy of segregation and extremely low wages (Abbas 2012), and towards supported or customized employment in integrated community settings (Nicholas et al. 2015). For example, the Workforce Innovation and Opportunity Act (WIOA 2014), which amended the U.S. law governing VR services for people with disabilities, reflects both an emphasis on competitive integrated employment and pre-employment transition services for youth with disabilities (U.S. Department of Education 2014). The latter include job exploration counseling, work-based learning experiences, and workplace readiness training, including development of social and daily living skills (Workforce Innovation Technical Assistance Center 2016). WIOA also extends the age for out-of-school youth with disabilities qualifying for such services from 21 to 24 (U. S. Department of Labor 2019).

Another law, the Higher Education Opportunities Act (HEOA 2008), is directed towards increasing PSE opportunities for those with ID or other cognitive impairments (including significant social skills deficits) through comprehensive transition and postsecondary training (CTP) programs. This is important because participation in a PSE program for individuals with ID—whether in an integrated CTP model where most instruction is provided alongside nondisabled college students or in a specialized program where it is not—is associated with positive employment outcomes. Specifically, Moore and Schelling (2015) documented that young adults with ID who had participated in either type of postsecondary program reported being employed outside home or school in the past two years at a higher rate (100%) than those who had not (53.5%). Likewise, Whittenburg et al. (2019) used VR data to show that young adults with ASD with some PSE experience had higher rates of

employment and increased weekly hours and hourly wages compared to those without it. This held even for those with significant functional limitations.

Young adults with ASD and typical cognitive ability (ASD-CA), who generally graduate from high school with a diploma around age 18 along with their neurotypical peers, confront some different obstacles than those with ID. One of these is the fact that people unfamiliar with ASD find it difficult to reconcile this group's cognitive ability with their social blindness, misinterpreting eccentric comments or abrupt behavior as intentionally rude, oppositional, or manipulative (Aspy and Grossman 2011). Those in this group may also exhibit poor daily living skills out of sync with their intellect. In a study of 417 ASD-CA adolescents, Duncan and Bishop (2015) found more than 56% had such a deficit—a troubling statistic since difficulty remembering to shower or set an alarm clock are consequential matters when one is trying to succeed in the workplace. Meanwhile, schools may stress academics for these students—their area of strength—in lieu of pivotal skills surrounding self-determination, self-management, and independence (Schall et al. 2014). There are certainly indications that these students are not receiving all they need. In a study on the post-high school educational and employment activities of 66 young adults with ASD, Taylor and Seltzer (2011) found that, compared with those with ASD-ID, those with ASD-CA were three times more likely to have no post high school activities at all.

While young adults with ASD-CA who received special education services in school may receive some short-term support for “transitioning youth” from a VR agency, the longer-term supports offered to those with ID throughout adulthood are rarely available. Yet research findings suggest that young adults with ASD-CA would benefit from sustained assistance whether in PSE or employment settings. For example, in a recent study of college-attempting ASD-CA students, 5 of 18 experienced a traumatic failure at college due to inadequate support in the face of social-communication challenges, rigidity, executive functioning deficits, and/or anxiety (Anderson and Butt 2017). Similar issues may impede this group's ability to succeed in the workplace as illustrated by a study focused on 259 ASD-CA adults. Baldwin et al. (2014) found that nearly half were unemployed, while close to 45% of those who were working were overqualified by education for their positions. Those who were employed often struggled with social demands, anxiety, and sensory issues at work. The authors concluded that adults with ASD-CA, “despite their capacity and willingness to work, face significant disadvantages in the labour market and a lack of understanding and support in employment settings” (p. 2440).

It is critical to investigate what lies behind discouraging statistics on employment outcomes for young adults with

ASD. Therefore, the objective of the current study was to explore early, employment-related expectations and experiences through first-person accounts of young adults on the autism spectrum and their parents. A better understanding of work-related challenges and obstacles may aid educators, clinicians, service-providing personnel, employers, researchers, and policy makers as they develop interventions and improve systems designed to assist adults with ASD in obtaining and maintaining employment.

Methods

This research utilized data drawn from a larger study designed to examine general outcomes for young adults with ASD. In this larger study, 35 mid-Atlantic parents (a mother, father, or couple), representing 36 young adults with ASD, took part in 90-min interviews. (The additional young adult was due to the fact that one family had two sons on the spectrum.) In 12 cases, the young adult with ASD was also separately interviewed. All young adults with ASD had left high school in the last 15 years. The Towson University Institutional Review Board (IRB) approved both parent (#15-X015) and young adult (#1611009343) protocols.

Procedure

To ensure the participants' privacy and to help them feel comfortable, most were interviewed by the first author in their homes, although a few opted for a different venue (e.g., the first author's university office). Because so little is known about the post high school experiences of young adults with ASD and their families, interviews were unstructured. They began with the open-ended question: “What has it been like for you and your son/daughter since high school's end?” Participants were asked to share whatever they felt was important not only at the transition from high school but before and after. The interviewer's technique was to remain mostly silent except to gently probe for additional information or to ask questions that would bring a participant back to transition-related topics. Parents and young adults spoke spontaneously about a wide variety of issues, including struggles during the school years, attempts at PSE, the fight for adult services, and hopes for the future. Comments related to anticipated or actual pre-employment or employment experiences are the focus of the current effort.

Participants

The current study is based upon 28 parent and 12 young adult interviews. Eight of the original 36 cases were not included as the young adult with ASD required “very substantial support” as defined in the Diagnostic and Statistical

Manual (DSM-5; American Psychiatric Association 2013, pp. 51–52). They were either severely ID with interfering behaviors ($n=5$) or CA with current intensive psychiatric issues ($n=3$). Their parents, focused on immediate needs, said little about pre-employment and employment issues, and none of these eight young adults themselves were interviewed. Hence, the narratives analyzed for the current study capture the experiences of 28 parents (mothers, fathers, or couples) and 12 young adults. Because most of these young adults had been diagnosed when the DSM-IV was in effect, labels now outdated were often used by participants (e.g., Asperger's Disorder) (American Psychiatric Association 2000). ASD status, presence of co-occurring conditions (e.g., anxiety), and cognitive level were based upon parent and/or self-report. The researchers did not have access to medical or educational records, and did not perform clinical assessments of participants. For demographic and diagnostic characteristics, see Table 1.

Analysis

All interviews were transcribed and uploaded into Atlas.ti qualitative analysis software. Through the lens of a grounded theory approach (Corbin and Strauss 2014), the constant comparative method (Glaser 1965; Boeije 2002) was then applied. Based on initial impressions of interview content, a first set of codes was developed to sort material into major categories (e.g., adult services, PSE). Next, interviews were independently coded. Any differences in initial codes were debated until an agreement on the most appropriate code(s) was reached. For the current study, the first and second author utilized a similar process to further analyze material designated as employment-related. Due to the diversity of the sample, codes were considered both in terms of recurrence and salience; that is, even a not-often-recurring code would be considered worth inclusion in the larger analysis if relevant to the study's objective (Buetow 2010).

Herein, “work” refers both to paid and unpaid pre-employment and employment experiences, including vocational or career preparation or training, volunteer positions, and internships. This choice was made because these young adults were at different places along a trajectory from high school student to employee, or from a first job to a more involved future job, depending on their cognitive ability, age, goals, and current setting (e.g., employed part- or full-time, in college, sitting at home). As shown in Table 1, young adults were placed into five categories based upon a simplified version of Taylor and Seltzer's Vocational Index for Adults with ASD (2012):

- *Competitive Employment without Support* ($n=3$) In a part- or full-time job in a typical employment setting without the aid of a VR or other service agency.

Table 1 Parent and young adult characteristics

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	28
Parent characteristics	
Parents interviewed ^a	
Mother only (%)	19 (68%)
Father only (%)	1 (4%)
Couple (%)	8 (29%)
Age of primary contact parent	54.2 (4.2)
Family income	
\$25 K–\$49,999 (%)	1 (4%)
\$50 K–\$74,999 (%)	2 (7%)
\$75 K–\$99,999 (%)	1 (4%)
\$100 K–\$149,999 (%)	11 (39%)
\$150 K or more (%)	13 (46%)
Marital status	
Married (%)	26 (93%)
Separated or single mother (%)	2 (7%)
Young adult characteristics	
Young adults interviewed	
Age (SD)	22.9 (3.1)
Gender—male (%)	22 (79%)
Race	
White (%)	22 (79%)
Black/African American (%)	4 (14%)
Other (%)	2 (7%)
Ethnicity—Hispanic (%)	2 (7%)
Current ASD diagnosis	
Autism (%)	7 (25%)
Asperger's (%)	12 (43%)
Other ASD (%)	9 (32%)
Age at diagnosis	
0–3.99 years (%)	9 (32%)
4–7.99 years (%)	4 (14%)
8 or older (%)	15 (54%)
Intellectually disabled (%)	9 (32%)
Residential status ^a	
Parental home (%)	23 (82%)
Apartment/DD (%)	1 (4%)
Apartment/independent (%)	1 (4%)
College dorm (%)	3 (11%)
Employment status ^a	
Competitive employment w/o support (%)	3 (11%)
Competitive employment with support/emp prep (%)	5 (18%)
Sheltered Voc/supported emp/day program (%)	7 (25%)
Postsecondary degree-seeking (%)	10 (36%)
No activity (%)	3 (11%)
Document at high school exit	
Certificate (%)	5 (18%)
Diploma (%)	23 (82%)
Co-occurring psychiatric conditions ^b	
Anxiety disorder (%)	18 (64%)
Depression (%)	11 (39%)
Obsessive compulsive disorder (%)	8 (29%)

^aDo not add to 100% due to rounding

^bCategories not mutually exclusive and so do not add to 100%

- *Competitive Employment with Support/Employment Prep (n = 5)* In a competitive job with the initial or ongoing support of a VR or other service agency or in an agency-sponsored employment preparation program.
- *Sheltered Vocational Setting/Supported Community Employment/Day Program (n = 7)* Performing tasks within a sheltered setting, often a day program, or participating in supported employment (with ongoing agency supervision). Recent federal legislation such as WIOA has emphasized a shift away from sheltered settings, and most families of participants engaged in repetitive tasks at their day program (e.g., envelope stuffing) hoped supported employment in the community would be possible in the future.
- *Postsecondary Degree Seeking (n = 10)* Attending a community or 4-year college part- or full-time.
- *No Activity (n = 3)* No daily activity at all; working 6 h or less; or just community activities with no vocational component.

Several measures were taken to increase the study's *trustworthiness* (Lincoln and Guba 1985), a term for rigor in the context of qualitative research. First, participants were asked to review their interview transcripts in a process called *member checking*. Infrequently, they identified errors, which were corrected. Second, new material that didn't fit previously emerging categories and themes led to a reconsideration and refinement of these in an approach termed *analyzing negative cases*. Lastly, two colleagues engaged in research on similar topics were invited to review the study's methods, results, and conclusions in a practice known as *peer debriefing*.

Table 2 Young adults on the autism spectrum and employment: themes and subthemes

Employment aspirations and potential

The advantages of work

(e.g., meaningful daily occupation, social engagement, self-esteem, wages, independence)

ASD-related strengths at work

(e.g., passion, attention to detail, loyalty, honesty, rule following, willingness to help)

Challenges of job finding and keeping

ASD-related challenges at work

(e.g., social difficulties, rigidity, anxiety, self-regulation issues, lack of speed/stamina)

Interviews and disclosure

(e.g., socially awkward, anxious, overly honest, managing stigma around ASD)

Accommodation: capacity and consequences

(e.g., acceptance vs. inflexibility, trauma, damaged self-esteem)

Differing parent and young adult work-related roles and views

When families can and can't help

(e.g., providing encouragement, arranging pre-employment experiences, interfacing with employment-related service providers, changing role)

Work satisfaction: differing perspectives

(e.g., parental worry about the future, young adult contentment vs. parental push for higher-level jobs)

Results: Themes and Subthemes

Three major themes, each with 2–3 subthemes, emerged from family and young adult narratives (see Table 2). Please note: To protect participants' confidentiality, all names used herein and some small, potentially identifying personal details have been changed. To provide context for the reader an indicator of (ID) or (CA) with age at time of interview is provided whenever a young adult with ASD is mentioned, e.g., John (ID-24).

Under the first theme, *Employment Aspirations and Potential*, parents and young adults with ASD expressed hope in a future that would involve meaningful daily engagement, including paid employment. The ideal job would make the most of a young adult's strengths while autism-related difficulties were ameliorated and/or accepted. Within the second theme, *Challenges of Job Finding and Keeping*, participants described the barriers faced whether young adults with ASD were in a job or laying the groundwork for one, as well as the consequences of failure. Contained in the third theme, *Differing Parent and Young Adult Work-related Roles and Views*, were parents' struggles to understand what part, if any, they should play when it came to their young adult and the workplace. At the same time, there was sometimes parent and young adult disagreement regarding what type of job was sufficient.

Employment Aspirations and Potential

Young people with ASD and their parents associated employment with numerous advantages in adult life. Participants' discussions of the possibility of meaningful work

were rich with belief in a young adult's potential, ideally aligned with unique, ASD-related strengths that would contribute to a fulfilling future.

The Advantages of Work

The perceived advantages of work included daily engagement that could structure a young adult's time and give it meaning; the importance of social interaction and a place to belong outside of the family home; financial benefits; and the independence and self-esteem associated with these.

For young adults with more severe ID, parents sometimes stressed daily occupation as the most important aspect of work. Jason (ID-26) was served by an adult agency offering what his parents viewed as too few hours of actual work. Jason's parents emphasized that employment continued to be a goal, and were seeking alternatives to ensure some amount of meaningful work was part of their son's future.

In contrast, the mother of 22-year-old Camille (ID-22), who had just started with an autism-focused adult agency, made it clear that paid employment was an important eventual objective:

They go out into a workplace. They try to habilitate as far as the different clients' abilities. For instance, Camille has worked in a setting where she has to serve food or make sandwiches... They're trying to figure out what the client's forte is or what they will succeed at in the workplace... The goal is that they will find their niche, and move forward and be productive and be able to work and make money and maybe live on their own one day. That's what they work toward.

Social aspects of work were also viewed as vital. William (CA-27) was employed in a comic book shop. His mother was pleased that he had made friends through work, with a social life revolving around role-playing games and other store-sponsored activities. Other parents also wanted daily structure and social interaction for their son or daughter. Bradley's (CA-22) father was worried about his son's isolation, and viewed a small job as at least a partial solution to this:

He works six hours a week for a woman that has a small picture framing shop... It gets him out and gets him skills and socialization and gets him out of the house and gets him out of his room.

Stanley's (ID-24) father emphasized that his son's part-time position at a grocery store brought both social benefits and self-respect:

Stanley has a lot of pride in what he does and he will do it well... I think in his current workplace, too, that social aspect is important. They do a lot of things for

staff with monthly celebrations or food in the break room. He's very social there because he's very kind, he's very genuine, and I think people really are drawn to him in that way.

Lee's (CA-21) mother described how important his job in a local grocery store was to his self-esteem, partly due to the financial benefits:

It is very important to him to have that sense of pride with his income and what he earns every week. He comes home and shows us the paycheck.

Though important, his paycheck was not the only source of Lee's pride. There were also important social aspects; he was smiling and animated as he shared that he'd recently been named "employee of the month."

ASD-Related Strengths at Work

Participants celebrated gifts associated with ASD, explaining how they could make a person on the autism spectrum an asset to an employer, and expressed a desire to find a setting where such gifts could come to the fore. One such gift was attention to detail. George's (CA-22) mother described how he displayed this strength during a community college auto mechanics program:

He is slower than anyone else but very meticulous... The other kids were just whipping... but what he also noticed was there were parts left over when these guys were working on things. Yeah, they were fast, but my son was noticing all the nuances in detail.

Julia's (CA-21) mother viewed imperviousness to people's negativity as an ASD-related strength. It had allowed her daughter to persevere in the face of rejection to become a top gift-wrap and candy fundraiser during high school—a trait she could picture helping Julia succeed on an entrepreneurial path.

It is probably because she had a social disability because if somebody told her 'no,' it was not piercing her heart. It was like, 'Okay, I am on to the next one.'

Some mentioned their young adult's passionate interests as a strength, remarking that any tie between these interests and assigned tasks would result in a very motivated worker. Lee's (CA-21) mother shared that he loved cars and how he would happily jumpstart them or shovel snow off them for his customers. Sam (CA-23), who was working on a lawn crew as part of his training through an adult agency, said:

I love nature... One of my job coaches is talking about passion, your skills and your passion. My skill and my passion have lined up and I found the perfect job.

Mitch (CA-22) was home after dropping out of college. His mother described how capable he was, and willing to help.

He's very handy... He is very responsible. We ask him to mow the lawn for us all the time, and he will. We have a computer problem, he will help us solve it. We have to install a lock, he can figure out by himself how to do it. Also, when we buy a piece of furniture, he can assemble it very well. He has his strengths.

Some of these young adults were described as rule followers and loyal to a fault. The father of Gregory (CA-28), a graduate student hoping for a federal job, declared:

The fact of the matter is that someone like Gregory is the last person who is going to be a security risk because he literally cannot lie... If you tell him that these are the rules, he is going to follow those rules. And there is nothing you can do to make him break the rules.

Challenges of Job Finding and Keeping

ASD-related challenges could make it difficult to obtain volunteer, internship, or employment opportunities, and to keep them once acquired. Interviews presented a particular barrier, while the question of whether or not to disclose one's ASD could further complicate matters. Employers' capacity for flexibility and understanding was variable. Parents and young adults alike rejoiced in success in the workplace, but failure could have lasting impacts on a young adult's confidence.

ASD-Related Challenges at Work

Although the strengths of those with ASD were many, so were issues that could interfere with success. Participants detailed the challenges associated with ASD, such as impaired ability to read and respond to social cues, anxiety, and issues with self-regulation or stamina.

Difficulties navigating social aspects of employment were an often-mentioned problem. Mitch's (CA-22) mother termed his IQ high but his emotional quotient (EQ) low, describing it as "a real disability" that "he cannot change." She linked that lack of social awareness to lapses in his personal hygiene as well as errors like showing up to a college career fair in a shirt from his teenage years that was several sizes too small.

Young adults with ASD who did obtain a position often found themselves in an unfamiliar environment, confronted with a new set of rules and especially at a disadvantage when it came to navigating social dimensions of the workplace. When Stanley (ID-24), with the help of a job coach, first

secured his part-time grocery store position, he was often late, had a hard time getting back from breaks on time, and spoke abruptly to the manager when calling for his schedule. His parents and job coach worked with him on all of these issues and he overcame them.

Joel's (CA-23) parents said their son tried so hard to follow rules such as being on time for work that he would inadvertently make social mistakes at his retail job. His mother explained:

His boss would walk up to open the door, and he'd beat her to the door because he'd get out of the car and walk faster than her... He gets focused on 'I'm supposed to be in work and clock in at 7:00.' He doesn't get that he's just run over four people to get there.

Self-advocacy skills were another area of weakness. Jonathan (CA-19) was working part-time at a grocery store; his mother explained:

Asking anything seems to be hard. It's really excruciating for him to try and say to a boss, 'I need some time off for a vacation,' or 'I'm not sure how to do this particular task.' That's hard for him.

Some parents mentioned that their young adult with ASD became overwhelmed or tired easily, thought "busy" environments difficult to deal with, or found it hard to quickly process information and complete pressured tasks. The mother of Marcia (CA-21), a culinary student at a community college, remarked:

I don't think that she could be in, at least initially, a restaurant that was hustling and bustling on a Saturday night and they want a salad made at some rapid pace. I think it needs to be something like at a bakery where you're just going to go and make 10 dozen cupcakes and spend all morning making it and baking it and plodding along. Something that's a restaurant that's high volume, high stress, people yelling, screaming, I don't think that would be good for her day one.

Self-regulation issues could likewise be an obstacle. Aaron (CA-23) ended up in anger management therapy after outbursts in a number of supported employment settings. George's (CA-22) mother explained how she wanted to insist he take on a summer volunteer position to get work experience, but ran into anxiety, rigidity, and "meltdowns like a 2-year-old again." This volatility made it difficult to arrange experiences that could build to eventual employment.

Related to this was the notion that young adults with ASD simply needed more time to grow, mature, and prepare for adult life than typical young adults. As George (CA-22) slowly made his way through community college, his mother pictured him achieving a 4-year degree by the time he was "thirty or thirty-five" based on his anxiety and

need to take things in small steps. Similarly, Julia's (CA-21) mother thought it would take her daughter longer to achieve independence than a typical young adult:

If you stretch it out, she can get there, but it is not like she is going to be ready at 22 and you are out the door. For her, it is going to be closer to thirty.

Interviews and Disclosure

Successfully getting an interview, and then being selected for a job over others, is arguably one of the biggest challenges even non-disabled adults encounter. For young adults on the autism spectrum this process was especially intimidating. Parents often feared that social awkwardness or other ASD-related issues would make it difficult for their young adults to compete for jobs. Warren's (CA-23) mother said:

I think Warren would be fine at a job if he could get one. I think it is the getting the job that is the part that would be really hard for him. How do you do an interview? How do you even fill out an application in a thorough way? How do you sell yourself? How do you do all of those things?

Elena's (CA-31) mother agreed, noting the social and anxiety-inducing nature of interviews. She related how her daughter described what sitting down for an interview was like for her:

She would say to me, 'The interview was terrible. There were two people that entered the room, that sat down, me in one chair and my Asperger's self in the other chair, just looking at me the whole time and screwing me up.' There couldn't be a more vulnerable, threatening situation for her than an interview. She's lost many, many, many jobs because of that... her anxiety is way more challenging than anything else she has.

According to his mother, typical interview questions were a struggle for Mitch (CA-22):

Every time he applied he got rejected. He applied for Target. Target actually called him to interview, but he would not say anything to try to advocate for himself or try to sell himself... They asked him, 'What is your weakness?'... He said, 'OK, my weakness is that my communications skills are bad.' Then they rejected him. He went to a lot of places and had the same problem.... the problem is his communication.

One dilemma young adults had to face at the outset of any job search was whether to reveal their ASD. Some parents and young adults urged honesty in the hope that this might lead to accommodation and acceptance. Others

recommended nondisclosure fearing discrimination. Marcia's (CA-21) mother was in the first group:

I would want to disclose to the employer just so they know and they're sensitive to it. I know that there's a faction that says that you shouldn't disclose, but to me there's no reason not to let people know.

Joel (CA-23) held a similar view, saying he was "open about disclosing" during interviews. Not doing so, he believed, could lead to issues later:

I figure if I tell people during the interview that means I have already, and that is the hardest part of the job search... Whereas if you tell them after you get the job, well, that could lead to awkward questions and why did you not tell me? I figure it is the least level of risk and plus, why not just be honest? I have Asperger's. At some point I am going to make some kind of social blunder, and I would rather they have advance warning than have to explain later.

Gregory (CA-28) disagreed, stating that he very rarely mentioned his ASD for fear of people's reaction. Similarly, Lee (CA-21) was clear that he was not going to tell his employer anything about it:

If there's a problem that I have to solve and I can't do it, I usually say that I have a sensitivity to it. I don't say I have a disability, I just say I have a very sensitive sort of a connection or something like that, and they usually get someone to help me out with it... My disability is completely invisible. They don't know I have a disability.

Accommodation: Capacity and Consequences

When a young adult disclosed their ASD, willingness of employers to be flexible, to offer support and understanding as needed, was critical. Kindness or awareness could make a major difference. When in college, Joel (CA-23) had interviewed for a key internship at a small publishing house and encountered such acceptance:

During the job interview, the internship interview, when I said I had Asperger's—do you know what that is?—the guy looked at me and said 'I do. You are hired.'

Joel came away from this experience with an excellent letter of recommendation and a feeling of pride.

Stanley's (ID-24) father described the kind of acceptance that made his son's success at the grocery store possible:

I think the people who are supportive are people who overlook the idiosyncrasies that might be different as long as they aren't affecting the actual job perfor-

mance. So if he paces, if he makes strange movements, if he maybe is loud, they're generally overlooking that kind of stuff...

Unfortunately, few parents and young adults described employers who were this accommodating. One issue mentioned was the need for employees to perform multiple roles; if a person couldn't move easily from one to the next, they were at a disadvantage. For example, with his computer skills, Lee (CA-21) was able to secure a one-day trial job at a small computer shop. Unfortunately, the owner declared he would have to be able to switch from working with computers in the back to dealing with customers up front—something the owner didn't think he could do. Larger stores were no more flexible. His mother said:

The job carving issue came up at Target... He would be perfect, we thought, in the electronics department... He could talk your ear off about cell phones and electronics. Well, number one, no, you cannot start there. Number two, they did not feel that with his disability his verbal skills would be good enough... They said, 'No, at Target you have to be able to do all of the jobs in the store. We do not just hire for little niches.'

This inflexibility and lack of understanding of ASD on the part of employers worried parents and frustrated young adults. Several of the young adults described feeling discouraged after a volunteer or employment opportunity did not work out. Elena (CA-31), who was laid off from her first job, said:

When I think of my unemployment period, I think of the year between that job and then going back to grad school. It was really tough, just finding the motivation to get up... It was just so hard to keep the motivation going.

George's (CA-22) mother had worked hard to get him a shelf-stocking volunteer opportunity only to have it fall apart when a new manager informed her son he could no longer sit on the floor while stocking the bottom shelves. He was so upset that he "could not bring himself to go back there."

Some young adults described losing an opportunity when their behavior or tone of voice was misinterpreted. Before starting graduate school, Gregory (CA-28) lost a position mowing lawns when two clients complained, one saying she didn't like the way he talked to her and the other saying he was "aggressive" and "arguing with him," although he hadn't intended to be confrontational. Keith (CA-20) could speak of little besides a distressing incident at his high school work placement where his "employers thought I was some kind of monster":

I didn't have a major nuclear meltdown... They thought I was having a major outburst when I actually

wasn't. My body language gave off that I was stressed that day, when it was really because I was quite hot... I was wearing two jackets at the time. I ended up walking past one person who was giving me instructions...they thought I was angry and aggressive, when I wasn't... I thought it was completely my fault, and I was really sad and angry with myself.

Joel (CA-23) felt discouraged after a series of employment failures. He described his first job, a retail position that lasted only three weeks, as "doomed from the start." The problem, he explained, was "mixing with the people... customers, co-workers..." Later, a job coach worked with another retail store to create a position for him, but this also did not work out when he could not restock items fast enough to satisfy the employer. For Joel, this was very painful:

I figure my parents, between public school, elementary school, private middle school, high school, and college, have spent thousands and thousands of dollars for tuition. I want to make that sacrifice worth it. They spent thousands of dollars to get me ready for the working world, and I want to show not just my parents, myself, the whole community: I can do this. I have already overcome so much."

Differing Parent and Young Adult Work-related Roles and Views

Parents cared deeply about their young adult's future. They might want to ensure that a volunteer opportunity, internship, or job was going well, but had limited insight into what was transpiring in such settings, and little ability to intervene. All too conscious of their own mortality and anxious to cultivate their son or daughter's independence, parents sometimes pushed their young adult to take on more. Young adults with ASD who were content in a current work situation did not always welcome this parental input.

When Families Can and Can't Help

To succeed in pre-employment and employment settings, most young adults with ASD needed opportunities, encouragement, and support. Many families worked hard to provide as much of this as possible, but there were limits to what they could do. Arranging volunteer opportunities was one way parents provided valuable experiences for their teens and young adults. Violet's (ID-20) mother facilitated a volunteer position at an animal shelter. Oliver's (ID-30) mother first got him volunteer hours at the public library, advocating over years to transform this into a paying part-time job.

Helping young adults find their way to formal paid positions was a complicated challenge. Parents described how they could encourage and guide their adult child, and

perhaps help with applications, but that direct involvement beyond this point was rarely appropriate. Patrick's (CA-21) mother tried to think of any work that would be a good fit and attempted to arrange it, but ran into barriers:

We called a dog walking service locally and it was a disaster... I tried to explain, 'Do you know what Asperger's is?' 'I don't know and I can't have anybody who's going to be difficult.' I basically said, 'OK, forget it.'

Marcia's (CA-21) mother made sure her daughter had athletic, academic, and volunteer opportunities, but during high school and community college found it more difficult to provide actual work experience:

She's top of the honor role, Dean's list. She has all of that. Just there's no replacement for her work experience...just no way to create an experience for Marcia of showing up for work, putting in your time card, someone gives you your task.

Similarly, Carlos' (CA-25) mother had been able to assist him in obtaining pre-employment experiences, including a summer job, during high school. When it was time for Carlos to secure a crucial, career-building internship during his studies at a technical institute, however, she could play no role. Without the internship, Carlos struggled to get a job after graduation. Already saddled with student debt, he eventually gave up his job search to enroll in community college.

William (CA-27) obtained his comic book shop job on his own. His mother felt her son's employer should understand his needs, and unsuccessfully tried to get job coaching in place. Meanwhile, she found it impossible to know what was taking place at work "unless you ask a hundred million questions and badger him":

I did not want to interfere a lot at work... I ran into his boss, and the boss would always say: 'He is doing a great job. He is hard working...he really knows his stuff. He apologizes a lot, but that is OK.' That is all I could get. The man did not want to talk more and I did not—you know it is odd when mommy does it. If you have a young adult with a more obvious disability and everybody knows they need a lot of help, it makes more sense if the parent is alongside of them giving them help. But when they look sort of neurotypical, it makes them weirder if mom is involved.

Work Satisfaction: Differing Perspectives

Parents sometimes worried that a young adult's current job offered too few hours, low pay, or no benefits, or viewed it as beneath their son or daughter's ability. Concerns about long-term outcomes often drove parents to push their

young adult to seek a better job, ask for more money, or otherwise improve their situation. In some cases, a young adult's views coincided with those of their parents. William's (CA-27) mother shared that he was very unhappy with the limitations of his current job:

He wants to get married and have children and he sees his disabilities as keeping him back from being an enticing possibility as a mate for somebody because he does not make much money... He makes ten dollars an hour but that is very hard for people in this area to live on. He can barely afford an apartment on that.

In other cases, a young adult was content with a current job while their parents, concerned about a time when they would no longer be able to help, lobbied for more. Elena's (CA-31) mother was troubled because her daughter, with a Master's degree, was not interested in seeking a higher paying job. However, Elena loved her job in the basement of a bookstore—a setting where she could avoid people and all the social anxiety that came with them:

One of the things I love about my job is that I do not answer phones at all... I wonder if it is a spectrum dream. It is very repetitive. I love it. It is not very challenging. There is not a lot of upward mobility.

With a recommendation from one of his college professors, Luis (CA-24) had acquired a good post-Bachelor's job. Later, he earned a Master's and his mother was urging him to find an even better position:

He graduated two years ago, came home, moved into the basement where he still resides. Now that he has a Master's degree, he really needs to be doing something other than this sort of startup job, but he's very, very linear so it's hard for him to think about looking at other jobs while he still has a job... He has a really hard time...having multiple focuses. He also thinks he's being disloyal by looking for another job while he still has a job. And he doesn't really understand that's kind of how that works.

Lee's (CA-21) parents kept looking for possibilities beyond the part-time grocery store job their son loved. His mother said:

I just feel like the missing piece right now is that next step in a career, trying to move from just a part-time retail job into something that has a future... We really want him to be able to be in a company with some benefits. Our goal is hopefully we do not want him to always be on SSI [Supplemental Security Income/disability benefits]... We are trying to look down the line. What happens when we are not around anymore?

Discussion

The first identified theme, *Employment Aspirations and Potential*, captured hope in a bright future for young adults with ASD. Wherever a young adult was on the autism spectrum, families expressed a desire for a future of continued gains and greater inclusion in the wider world, including the world of work. Those who described their son or daughter as more severely ID tended to focus on meaningful daily occupation as the most significant advantage of work. As cognitive ability increased, so did hopes for additional employment-related benefits, up to and including financial independence. Some advantages of work, such as social engagement and self-esteem, were important regardless of a young person's cognitive profile.

Families also celebrated the strengths that often accompany autism, especially those that might prove valuable in the workplace. Passion, willingness to help, attention to detail, loyalty, honesty, and rule following were all mentioned. Both scholarly and anecdotal accounts cite similar traits, as well as reliability, focus, accuracy, consistency, logical reasoning, excellent pattern recognition, and an enjoyment of repetitive tasks uncommon among neurotypical people (Lorenz and Heinitz 2014; Murray 2020). Some of these characteristics likely relate to the low turnover rate reported for employees with disabilities, including autism (Nardick 2019):

And what we found was the turnover and absentee rate with these individuals [with disabilities] was much lower, and the employee engagement rate was much higher. On paper, the hires we'd made with disabilities were actually outperforming other people who showed up to work every day bored and unhappy. (p. 2)

The second theme, *Challenges of Job Finding and Keeping*, involved obstacles that stood in the way of hoped-for success. Some of these, like rigidity or difficulty navigating social situations, were associated with having an ASD. In many cases, it was apparent that such issues had not been sufficiently mitigated before pre-employment or employment opportunities were on the horizon. For example, George's (CA-22) overwhelming anxiety, Aaron's (CA-23) explosive temper, and Gregory's (CA-28) tendency to speak in a tone that others took as aggressive clearly interfered with their ability to work. The extent to which such challenges could have been addressed earlier, through families, schools, or adult agencies remains unclear.

One phenomenon of note related to age. There was a rosier cast to the narratives of younger adults with ASD and their families. For example, Jonathon (CA-19), who

was just starting at a 4-year college, was only mildly concerned about future employment, while Gregory (CA-28), who was about to finish a Master's degree, was extremely apprehensive about job prospects. The same could be said of parental views regarding adult services. Belinda's (ID-20) mother was optimistic about her daughter's very new agency placement and the potential for supported employment. In contrast, Oliver's (ID-30) parents were so disillusioned with the services on offer they had turned to self-directed services (where parents apply to manage their child's state disability funds and program). They were arranging small jobs for him on their own.

Indeed, many barriers to employment had less to do with a young adult's characteristics and more to do with larger systems and external realities, including prejudice, organizational inflexibility ("we do not just hire for little niches"), and lack of services. (In their investigation of predictors of employment and PSE outcomes for youth with ASD receiving VR services, Migliore et al. (2012) found less than 50% received job placement services and only 10% received college services.) Formal employment support was more likely to be in place for a young adult with ID, such as Stanley (ID-24)—whose job coach helped ease his way into his grocery store position—but even this did not guarantee success. Joel (CA-23) was about to lose his retail job despite all the help his job coach could muster. Most of the ASD-CA did not receive much assistance, either never qualifying for it or having aged out of limited "transition-age" VR support. Whether looking for a job without benefit of PSE, after dropping out of college, or after college graduation, they were often on their own.

There have been attempts to improve matters for young adults with disabilities, including ASD. For example, the Higher Education Opportunity Act (HEOA 2008) provides grants to institutions of PSE for model Transition and Post-secondary Programs for Students with Intellectual Disabilities (TPSID)—programs meant to improve on existing CTPs by providing inclusive college classes, independent living skills, self-advocacy skills, and work experiences necessary to eventual employment, including internships (U.S. Department of Education 2015; Lee and Rozell 2018). It is important to note that HEOA (2008) expansively defines "student with an intellectual disability" to include not only those with "mental retardation," but those who received special education during the school years and have "significant limitations" in "conceptual, social, and practical adaptive skills" (section 760). Hence, cognitively able individuals with ASD who struggle with such skills may qualify for HEOA programs. Another key piece of legislation, the VR-associated Workforce Innovation and Opportunity Act (WIOA 2014), expanded pre-employment services to youth with disabilities, including "more opportunities to practice and improve their workplace skills, to consider their career interests, and

to get real world work experience” (U.S. Department of Education 2014, p. 1). The narratives of the families and young adults taking part in this study demonstrate the importance of such pre-employment services.

An urgent question is to what extent these programs are reaching young adults with ASD. Few of the families and young adults interviewed seemed to have accessed the opportunities envisioned in this legislation. Warren’s (CA-23) mother was sure he could do well in a job if he could get through an interview, but had no idea how he’d gain such a skill. She was paying for a private college support program but her son was receiving no public services. Marcia’s (CA-21) mother fretted about her capable daughter’s lack of work experience; she went straight from high school to community college with no employment practice except volunteer opportunities her mother arranged. Besides a 6 h-a-week job his father found, Bradley (CA-22) was sitting at home after failing at college, as was Patrick (CA-21). Although some of the older participants had gained full-time competitive employment—Luis (CA-24), William (CA-27), and Elena (CA-31)—others found it difficult to get through the necessary steps to get a job. This included Carlos (CA-25) and Gregory (CA-28), who were unable to secure crucial internships highly recommended during their postsecondary programs that might have translated into jobs after graduation. Neither had been able to access a CTP or TPSID although they clearly needed the kind of assistance these programs or some kind of ASD-specific VR services could provide.

Deciding whether or not to disclose their disability was a difficult question for young adults with ASD-CA who sought employment without the assistance of any disability-focused agency. Like others with disabilities not immediately apparent (e.g., chronic illnesses, learning disorders), they struggled with the question of whether to declare their disability from the outset (Santuzzi et al. 2014). They had to weigh the understanding that might be elicited from others in the workplace against potential stigma and discrimination. As pointed out by Johnson and Joshi (2014), individuals with ASD face complications beyond those of someone with fibromyalgia or dyslexia when confronting this question. First, their disability may be less invisible than they believe; others may be able to infer they have ASD from their behavior. In addition, the act of disclosure requires a delicate social calculation regarding the right time and place to disclose, and the most appropriate and receptive person to approach. Individuals with ASD are at a disadvantage when it comes to such matters. There is a need to explore how to support young adults with ASD through the disclosure decision—not just whether to disclose, but when, how, and to whom.

Young adults with ASD who had experienced any kind of failure in a pre-employment or employment setting often expressed feeling traumatized. For example, Keith (CA-20) was labeled aggressive the 1 day the person who’d been

responsible for his small pre-employment opportunity didn’t show up to work; the placement ended, leaving him upset for months afterward. Other researchers have reported similar upheaval caused by such experiences. Sosnowy et al. (2018), who interviewed 20 young adults with ASD and 21 parents, stated that some parents “described their child having one negative experience and refusing to return, ending the volunteer or work position” (p. 35). This may explain why Taylor and DaWalt (2017) found half of the 36 youth with ASD in their study experienced a postsecondary work or educational disruption in the 2–3 years after high school. There is a clear need to educate those involved in providing pre-employment or employment experiences so that autistic traits, such as social blindness or an unusual tone of voice, are not interpreted as intentionally rude or aggressive, while any necessary feedback is provided in a sensitive manner that takes into account the vulnerability of some young adults with ASD.

The third theme, *Differing Parent and Young Adult Work-related Roles and Views*, touched on parental engagement in the employment issues of sons and daughters. Whereas parents of neurotypical young adults relinquish direct involvement in their employment-related affairs, parents of young adults with ASD—conscious of their young adult’s needs and accustomed to years of advocacy and crisis management—often felt driven to intervene. Their intensity seemed rooted in longstanding worry about what would happen to their adult children once they passed away (Ludlow et al. 2011; Marsack-Topolewski and Graves 2020). Beyond worries about the future was the fact that parents themselves were affected in the near term by young adult employment situations gone wrong, whether these failures led to continued dependence or young adult depression. Keith’s (CA-20) mother was distraught that she had been unable to prevent, fully investigate, or even understand the incident that damaged her son’s self-esteem and left him so unsettled. William’s (CA-27) mother worried about her inability to gain insight into how things were going at the comic shop, desperate to share her insights with her son’s boss. Unfortunately, well-intentioned parental interference in a young adult’s employment setting has the potential to backfire.

It is perhaps not surprising that parent and young adult views on the long-term suitability of jobs sometimes clashed. Young adults who did manage to secure a comfortable position tended to resist moving on from it. This may be partly due to the routine-loving nature of those with ASD. It may also be partly due to a recognition that it was not so easy to find a job that was a satisfactory fit. In contrast, parents of young adults, especially those with ASD-CA and no services, sometimes pushed for job growth and change, leading to tension. Again, this was attributed to parents’ longer-term concerns about their child’s ability to achieve financial independence: a salary adequate to support themselves and

robust health insurance. This last matter was especially critical if the young adult would have ongoing mental healthcare needs—a likely situation considering the large percentage of adults with ASD who have co-occurring psychiatric conditions such as anxiety, depression, or bipolar disorder (Croen et al. 2015).

Of such conditions, anxiety was especially common among the young adults in this sample ($n = 18$; 64%). This may help explain the fact that very few of the young adults, whether by their own or their parent's report, were focused on much past the immediate future. For example, George (CA-22) said the anxiety produced by contemplating the future during high school had been extreme, and he had only been able to think “a few minutes ahead.” It is interesting to note that other researchers have reported comparable difficulties imagining and planning for the future among young adults with ASD. Cheak-Zamora et al. (2015) found future-focused parents struggling to motivate their youth with ASD towards education and employment, while the youth seemed “overwhelmed by the future and, as a result, wanted to focus on the present” (p. 552). Sosnowy et al. (2018) likewise discovered that parents were concerned about quality of life and security in the long-term while young adults had only a vague sense of the future. It may be that this reluctance to think very far into the future impedes early planning about careers and adult life, including taking the interim steps needed to achieve longer-term goals. Could the delayed maturity some parents described in their young adults with ASD also be connected to this? How often do even cognitively able individuals with ASD need until they are “thirty or thirty-five” to reach the milestones that their typical peers reach in their late teens or early twenties?

The extent to which youth with ASD have the chance to acquire, during childhood and adolescence, the types of experiences that build towards employment also remains unclear. Consider the “developmental milestones for productivity occupations in children and youth” (p. 75) described by d'Entremont et al. (2017). These include household or agricultural chores, caring for oneself and others (e.g., looking after siblings), volunteering, and paid work. A typical 20-year-old's first resume might list babysitting, volunteering at the food bank, and a part-time job waiting tables. ASD-related issues likely interfere with access to such opportunities. How far do young adults with ASD lag behind typical peers in this realm, and how can they make up lost ground once they are far past the age at which typical young adults achieve these employment-related milestones?

In addition to preparing young adults with ASD for employment, it is necessary to reform external systems not generally configured to accommodate them, whether high schools, agencies, or corporations. Fortunately, there are examples of programs attempting to improve employment outcomes for those on the autism spectrum by directly

addressing some of the barriers encountered by young adults with ASD described by the current study's participants.

Wehman et al. (2017) used a randomized controlled trial to demonstrate the success of Project SEARCH, a high-school-to-work program modified specifically to meet the needs of students with ASD who also have cognitive and behavioral challenges. It involved 9-months of job training during the last year of high school, and featured placement in community organizations such as banks or hospitals. Internships with support, classroom time at the business, and assistance finding employment upon completion were all components of Project SEARCH, as was the active involvement of students, families, schools, VR agencies, adult service-providing agencies, and employers. Students who participated in this program acquired community-based employment by 12 months post high school graduation at a significantly higher rate than those who did not (87% vs. 12%).

There are also corporations attempting to support employees with ASD. For example, inspired by an executive whose son is on the autism spectrum (Lewis 2014), Walgreens (n.d.) has two programs designed to help adults with disabilities succeed—*Retail Employees with Disabilities* and *Transitional Work Group*. These train customer service and warehouse employees, respectively. Partnering with local adult service and VR agencies, Walgreens provides classroom and in-store training for individuals with ASD with the potential to lead to employment. Walgreens' website provides links to adult agencies that are already coordinating with them. Their explicit policy is to set the same expectations and provide the same pay for nondisabled and disabled employees.

SAP, an enterprise application software company, has set a goal to hire hundreds of individuals on the autism spectrum (Chu 2015). Their program, focused upon individuals with ASD-CA, takes a number of approaches that address identified problems including difficulty interviewing, not understanding workplace culture, conflicts with co-workers, and issues that arise when the one supervisor who understands the person with ASD is absent. For example, SAP replaces the typical job interview with a Lego robot-building group activity during which observers can assess an applicant's ability to follow instructions and get along with others. Successful candidates take a four-week course on workplace culture to help them learn to navigate the corporate setting. Meanwhile, future colleagues—not just co-workers, but security guards and cafeteria staff—receive training in autism. Perhaps most significant is the multifaceted support team placed around each employee with ASD:

There is, of course, the person's manager. But there's also a manager's rep deputized to step in if the manager happens to be out. There's a specially trained member of the human-resources team. There's a state-

paid, onsite job coach. And there's the *Autism at Work* mentor—an employee who has volunteered to be an in-office buddy.

An alternate pathway to employment success—one suggested by Julia's (CA-21) mother—also bears mention: entrepreneurship. According to the U.S. Bureau of Labor Statistics (2019), people with disabilities are about 50% more likely to be self-employed compared to those without disabilities (10% vs. 5.9%). It is certainly clear that parents unable to find employment opportunities for their young adult with ASD have sometimes created their own through development of businesses designed to make the most of their strengths (Kaufman 2019). Many ventures begun for the sake of one adult with ASD expand to hire more. Days worked and hours per day can be as flexible as they need to be. Whether making and selling gourmet popcorn, producing soap and candles, running a bookstore, or scanning mammography images for anomalies, adults with ASD can thrive in businesses built to provide both employment and community (Stolman 2018).

All of these promising model programs reflect what has been called “an ecosystem approach to employment” (Nicholas et al. 2018, p. 264). In brief, they acknowledge the need to address not just the skills of an individual with ASD, but the intersecting systems surrounding them such as families, high schools, agencies, and employers.

Recommendations

The findings of the current study point to the need for future research in three areas.

Recommendation #1

Determine how to effectively prepare young adults with ASD across the spectrum for the working world while making the most of their strengths.

There is a need to identify what specific challenges are interfering with the workplace success of young adults with ASD, and to develop and deploy effective interventions with the workplace in mind. If low stamina, self-regulation issues, or overwhelming anxiety are common, how can these be better addressed in childhood and adolescence? How can they continue to be addressed if not largely resolved by the time a young adult with ASD leaves high school? A related issue sometimes broached by parents was their young adult's lack of resilience such that one upsetting incident could end a volunteer or employment opportunity. Exploring the nature of this phenomenon, and methods to increase resilience, is essential.

Delayed maturity and readiness for adult life in young adults with ASD was also mentioned. An important question is how common it is for a young person with ASD to need until “thirty or thirty-five” to be ready for full independence, and to what extent they could have been ready sooner with the right support. If the developmental trajectory of some young adults with ASD is significantly different from that of typical peers, this may impact the design and pacing of pre-employment experiences and job-related training intended for them. Across all of these possibilities, there is also a need to discern how needs and approaches should vary based on intellectual capacity, co-occurring conditions (e.g., anxiety), and other factors.

Finally, what is the best way to design jobs or careers based on the gifts of those with ASD? More research is needed on what Wong et al. (2018) called “positive autism” (p. 19)—employment strengths related to ASD. One valuable approach may be analyzing the models developed by a variety of problem-solvers building programs based on the strengths of people with ASD, including those designing TPSIDs under HEOA, model agency or corporate programs, and family-driven entrepreneurial enterprises.

Recommendation #2

Discover how to best assist parents of young adults with ASD working to support achievement of employment milestones.

Parents of young adults with ASD would surely benefit from support around issues like those experienced by the current study's participants. These include frustration that their young adults with ASD encountered so many barriers to employment, sadness when they couldn't prevent discouraging failures, and the desire to intervene (often thwarted) if they felt things were going amiss in the workplace.

A recent pilot program trained parents of youth with ASD to advocate for adult disability services with encouraging results (Taylor et al. 2017). Similar programs for parents could be developed that focus on how to guide a young adult towards employment, including knowing key agencies and how to best interface with them. A central feature of this would be an ASD-specific transition-to-adulthood orientation that normalizes a parent's changing role, acknowledging the intensity of their advocacy throughout their young adult's childhood and how the shape of this may change as their son or daughter matures. Recognizing the natural tension between their desire to intervene and their hopes for their young adult's independence may help them bear the discomfort of respecting new boundaries, such as permitting job coaches and other professionals to take the lead in communicating with employers. In addition, parents should be made aware of how to appeal or advocate if a program is failing their young adult. Introducing the possibility of

alternatives, such as “self-directed services” or the entrepreneurship path, with examples of how these have been successfully navigated by others, would also be worthwhile.

Recommendation #3

Collect and disseminate key insights into the multiple, intersecting systems that impact employment for young adults with ASD; identify best practices within and across these systems.

It is crucial to understand how policies and practices within high schools, colleges, VR or adult service-providing agencies, and employing organizations affect employment outcomes for young adults across the autism spectrum. How can high schools better prepare their students with regard to social skills, daily living skills, and other deficits that often impede employment success, especially with regard to those with ASD-CA who are often overlooked when it comes to such matters? What is happening throughout the Transition Individualized Education Program (IEP) process in high schools? How often does a goal of PSE come without a back-up plan and no link to a VR agency in case college does not work out? Similarly, who is and is not benefitting from model programs implemented under HEOA—in the context of PSE programs meant to lead to employment—and WIOA, which is meant to help people with disabilities gain access to the education, training, and support they need to succeed in the workplace through the VR system? How could this situation be improved?

It is likewise important to capture and share key lessons of model programs taking place in varied contexts (e.g., Project SEARCH, Walgreens, SAP, entrepreneurial enterprises). The ability to understand the key elements of these successes, and to help people and organizations reproduce them, has the potential to positively impact the lives of many young adults with ASD and their families.

Limitations and Strengths

This study was subject to several limitations. First, participants were from a limited geographic area. Though diverse in terms of intellectual ability and ASD comorbidities, the participants were also largely white and from a higher socioeconomic status. Next, ASD and other diagnoses were based on parent or self-report; they were not confirmed by clinical records or direct assessment. Finally, parents outnumbered young adults with ASD as participants, leaving individuals with ASD underrepresented in comparison to parents.

The study also features a number of strengths. With forty participants, who represented the breadth of the autism spectrum and a wide age range, descriptions of experiences were rich and varied. Twelve young adults with ASD participated,

ensuring at least some of their voices were heard. The open-ended nature of interviews meant experiences shared were not pre-framed by narrow, employment-specific questions; concerns that arose did so spontaneously and within the context of a larger discussion of life after high school. The study also reflects priorities set forth in the Interagency Autism Coordinating Committee’s 2016–2017 Strategic Plan (2017) by examining what undergirds the discouraging statistics on young adult outcomes reported by those utilizing the NLTS-2 and other population-based data sets.

Conclusion

Young adults with ASD and their families celebrate the gifts of those on the autism spectrum, and hope for a bright future. At the same time, many are conscious of the barriers that hinder these young adults’ ability to find and maintain meaningful employment. These include a lack of pre-employment experiences, insufficiently addressed interfering issues (such as anxiety or social skills deficits), and external systems unmindful of their strengths and needs. Future research should further explore how to address young adult vulnerabilities, support and empower parents, deploy successful elements of model programs, and improve less-than-ideal practices in high schools, adult agencies, and the workplace.

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Author Contributions CA conceptualized the study; conducted all interviews; performed coding and qualitative data analysis; and drafted the final manuscript. CB and CS performed coding and qualitative data analysis and contributed to the manuscript. All authors read and approved the final manuscript.

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Compliance with Ethical Standards

Conflicts of interest The authors declare that they have no conflict of interest.

Ethics Approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. The Towson University Institutional Review Board (IRB) approved

both parent (#15-X015) and young adult with autism spectrum disorder (#1611009343) study protocols.

Informed Consent Informed consent was obtained from all individual participants included in the study.

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