

# Young Adults on the Autism Spectrum at College: Successes and Stumbling Blocks

Connie Anderson<sup>1</sup>  · Catherine Butt<sup>1</sup>

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**Abstract** There is limited information on outcomes for young adults with autism spectrum disorder (ASD), including achievement at college. Qualitative interviews were conducted with 18 families reporting a degree-seeking college experience for their young adult with ASD. Interview transcripts were analyzed using a grounded theory approach. Four themes surrounding success and failure at college emerged. *Preparation Beyond Academics* involved challenges associated with ASD, such as social, executive functioning, and mental health issues, and to what extent these had been addressed prior to leaving high school. *Student/College Fit* related to whether a student's capabilities were matched to college location, size, and culture, while *Campus Supports* and *Family Supports* concerned assistance provided by colleges and families, respectively. Implications for future practice are discussed.

**Keywords** Autism spectrum disorders · Adult outcomes · Postsecondary education · Qualitative research · Grounded theory

## Introduction

The reported prevalence of autism spectrum disorder (ASD) in the United States has increased to 1 in 68 (ADDM Network Surveillance Year 2012 Principal Investigators 2016), and ever more students on the autism spectrum are exiting high school to confront the transition to

adulthood (Gerhardt and Lainer 2011). Though they often possess gifts, such as a keen memory for detail or passionate interest in a specific topic, they also face a number of ASD-associated challenges. These include social-communication difficulties and restricted, repetitive behaviors, activities, and interests (American Psychiatric Association 2013).

Researchers have utilized data from the U. S. Department of Education's National Longitudinal Transition Survey (NLTS-2) to gain insight into postsecondary outcomes for young people with ASD. Results have been concerning. Compared with young adults with other disabilities, those with ASD are least likely to live independently (Anderson et al. 2014); have worse employment outcomes (Roux et al. 2013); and are at higher risk for having no involvement with employment or postsecondary education in the first 2 years after high school (Shattuck et al. 2012).

The current study is part of a larger project aimed at understanding what circumstances underlie these statistics. Towards that end, families with young adults from across the autism spectrum participated in unstructured interviews regarding life after high school. When adult children were intellectually disabled, families tended to emphasize experiences with service agencies. When adult children were cognitively able, on the other hand, families tended to focus on experiences with institutions of postsecondary education. The latter group is the focus of this study.

Attending college for the first time involves a transition that has been termed "stressful and disruptive" even for typical teenagers (Conley et al. 2014, p. 195). They must abruptly meet higher academic standards, taking sole responsibility for tracking assignments and meeting deadlines. They also may be living away from home for the first time, building new identities, managing new relationships, and coping with loneliness (Drake et al. 2016; Shaver et al.

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✉ Connie Anderson  
connieanderson@towson.edu

<sup>1</sup> Department of Interprofessional Health Studies, Towson University, 8000 York Road, Towson, MD 21252, USA

1985). The limited research available suggests this change is even more daunting for the 36% of young adults with ASD who attempt college (Roux et al. 2015). For example, Cai and Richdale (2016) describe the consequences of social-communication difficulties on campus, including the struggle to interact effectively with professors. Cullen (2015) highlights difficulties negotiating group assignments and building relationships with fellow students, while White et al. (2016) examine how college success is impacted by conditions that frequently co-occur with ASD. These range from mental health concerns, such as anxiety (Buck et al. 2014), to executive functioning (EF) deficits. These involve problems with “working memory, planning, flexibility, and organization, in the service of problem solving and behavioral regulation” (Wallace et al. 2016, p. 1071).

There has been little research directed at potential connections between disability support in high school and college success for intellectually able students with ASD. Depending on needs acknowledged, services delivered, parental advocacy, and quality of transition planning, these students may receive quite different levels of support during the high school years. With an “autism” label, one might assume all would qualify for an Individualized Education Program (IEP)—a document establishing special education and related services under the Individuals with Disabilities Education Act (IDEA 2012). To qualify, however, a student’s disability must be deemed to have a negative impact on educational performance. This is not always the case for cognitively able students with ASD. If the threshold for an IEP is not met, a student may receive a 504 Plan. This is a document associated with Sect. 504 of the Rehabilitation Act (2012), a statute aimed at preventing disability-based discrimination. Because these supports are less extensive than those provided by an IEP, 504 Plans have been termed a “consolation prize” (Zirkel and Weathers 2016, p. 67). According to deBettencourt (2002), “Schools may offer less assistance and monitoring with Sect. 504 because there are fewer regulations by the federal government instructing them, especially in terms of compliance” (p. 22). Of course, high school students with ASD may receive no support at all under a number of circumstances, including total denial of need by a public school or attendance at a private school not covered by federal mandates.

Thus far, research directed at college experiences for students with ASD has utilized questionnaires, focus groups, or interviews with current students and their family members. Though valuable, these approaches omit the experiences of those who are no longer on campus, whether they have graduated or failed. Neither do they examine possible connections between high school supports and college outcomes. The current study’s open-ended interviews were designed to fill such gaps. Initially, the objective was to

capture broad experiences surrounding college. As parents and young adults began to share their experiences, however, specific issues related to success or failure on campus came to the fore. These included an overemphasis on academics in high school at the expense of social and other skills; the need to match student capabilities to campus size and culture; and the importance of appropriate supports at college.

## Methods

The Towson University Institutional Review Board (IRB) approved both arms of a single study: one involving interviews with young adults with ASD and one involving interviews with their parents. To participate, a family had to have a young adult with ASD who had left high school within the past 15 years. The young adult could be anywhere on the autism spectrum in terms of cognitive functioning, ability to self-regulate, and other factors. The intention was to capture a broad range of experiences both during and after high school without presuming anything. Too little is known about adult circumstances and outcomes to justify a priori categorization of young adults with ASD or judgements about what issues will be key for any specific group.

## Participants

Families from the mid-Atlantic region were recruited via email and social media, often with the help of local autism advocacy organizations. In addition, participants sometimes shared study invitations with other affected families creating a “snowball sample.”

The first author conducted all interviews. Of 35 families participating in the broader adult outcome study, 18 shared information about a young adult’s 2- or 4-year college experience. In 11 of these 18 cases only a parent was interviewed, while in seven both a parent and an adult son or daughter were separately interviewed. Parent interviews lasted 60–90 min. Young adults seemed to tire sooner; their interviews lasted 30–45 min. Interviews most often took place in the interviewee’s home, though meeting rooms in public libraries and the first author’s university office were also used for this purpose. Demographic and diagnostic information, collected via a *Pre-interview Questionnaire* immediately prior to parent interviews, are provided in Table 1.

Interviews were unstructured, featuring open-ended questions meant to elicit whatever was most important to the respondent and to reveal issues that might not have been considered by the researchers. For example: “What was it like for you as you came to the end of high school?”

**Table 1** Participant characteristics

N	18
Parent interviewed	
Mother only (%)	13 (72%)
Father only (%)	1 (6%)
Couple (%)	4 (22%)
Age of primary contact	53.9 (4.1)
Family income	
\$25 K–\$49,999	1 (6%)
\$50 K–\$74,999	1 (6%)
\$75 K–\$99,999	–
\$100 K–\$149,999	5 (28%)
\$150 K or more	11 (60%)
YA age (SD)	22.9 (3.2)
YA gender	
Male (%)	14 (78%)
Female (%)	4 (22%)
YA race	
White (%)	14 (78%)
Black/African American (%)	3 (17%)
Asian (%)	1 (6%)
YA ethnicity	
Hispanic (%)	1 (6%)
Non-hispanic (%)	17 (94%)
YA current ASD diagnosis	
Autism (%)	1 (6%)
Asperger’s (%)	13 (72%)
PDD-NOS (%)	2 (11%)
Other ASD (%)	2 (11%)
YA age at diagnosis	
0–3.99 years (%)	3 (17%)
4–7.99 years (%)	3 (17%)
8 or older (%)	12 (66%)
Current status <sup>a</sup>	
4-Year college—graduated (%)	4 (22%)
2-Year college—attending (%)	5 (28%)
4-Year college—attending (%)	4 (22%)
2-Year college—failed/took PT job (%)	2 (11%)
2 or 4-Year college—left in crisis (%)	5 (28%)

<sup>a</sup>These add up to more than 100% as two individuals are counted twice. One currently enrolled student and one college graduate had suffered a crisis at college, but recovered

What happened after that?” The interviewer probed for additional details whenever important topics were mentioned (e.g., experiences with service agencies, employers, colleges). Interviews were digitally recorded and then transcribed. All names have been changed to protect participants’ privacy.

## Analysis

The *constant comparative method* (Glaser 1965; Boeije 2002) associated with a grounded theory approach (Corbin and Strauss 2014) was utilized. Both authors reviewed parent and young adult narratives and sought to inductively identify common intersecting themes. First, Atlas.ti qualitative analysis software was used to code post high school experiences by major topic (e.g., Services, Employment, Postsecondary Education). Next, files were merged so that both authors’ codes appeared side by side. Where the authors were in agreement, a code remained. If there was disagreement, the meaning of the narrative was debated until a final decision on a code was reached.

For the current study, all material relating to Postsecondary Education was extracted and examined for themes following the same procedure described above. Themes were considered both when they were frequent or *salient*, that is, relevant to major questions about college success or failure even if not commonly reported (Buetow 2010).

To address *trustworthiness*, a term that encompasses various aspects of rigor in qualitative studies, the authors strove to recognize, question, and account for any potential bias in their reactions and, hence, this analysis. They also engaged in *member checking* by asking participants to review transcripts to insure that their thoughts had been captured accurately. They *analyzed negative cases*, continually questioning the boundaries of themes and subthemes. For example, a later occurring interview might reveal that a theme had been defined too narrowly and should be expanded. Lastly, they engaged in *peer debriefing*. This involved inviting colleagues not associated with the study to critique the analysis and results, challenging the research team to reexamine assumptions made, thought processes undertaken, and conclusions reached (Lincoln and Guba 1985).

## Results

Families and young adults with ASD shared diverse experiences related to postsecondary education. At the time of the interview, four (22%) young adults had completed a Bachelor’s degree; nine were attending a 2 or 4-year college ( $n=5$ ; 28% and  $n=4$ ; 22%, respectively); two (11%) had dropped out of a community college and were working part-time jobs; and three (17%) were forced to return home after suffering a crisis while living at college. (In addition, one currently enrolled student and one college graduate had suffered such a crisis, but recovered.) Four main themes relating to how well a student was able to cope and perform at college emerged from participants’ varied narratives: *Preparation Beyond Academics*, *Student/College Fit*,

*Campus Supports*, and *Family Supports*. A summary of themes and subthemes is provided in Table 2.

### Preparation Beyond Academics

How well the transition from high school was planned, and to what degree strengths were encouraged and weaknesses ameliorated, was crucial. High schools and families both had roles to play in addressing social deficits, learning disabilities, EF issues, mental health challenges, and life skills, including independence and self-advocacy.

#### *Importance of a Robust High School Transition Process*

IDEA requires a formal transition process for students with special needs (U.S. Department of Education 2007), but experiences with this process varied. In some cases, parents were quite satisfied. Speaking of their high school IEP team, Cameron's father said:

They talked about transition very early on and probably starting in ninth grade. They brought the Vocational Rehabilitation (VR) rep into one of the IEP meetings so we got to meet someone there, talk through VR services... So I think from a school perspective they really sort of rallied around him and really provided a lot of support.

The IEP process itself was sometimes used to develop self-advocacy skills that would be needed at college. Sean's mother explained:

Every single time his annual review was coming up for his IEP all the way through high school, I just had him read the draft. I am like, 'You tell me what you think. Does this make sense? Do you need this? Does this best describe you? What about these goals?' So he was a full participant in the IEP development and knew very well what accommodations he had. So when we sat there with that college person, he said, 'I am really, really going to need this one and this one.' And she is like 'Great, groovy, got it.'

However, not everyone was pleased with how the transition process went. Declared Gina's mother:

The high school transition teacher they had was useless which was very frustrating. First of all, I initiated all the meetings. There were meetings she forgot to come to. When she finally got in the room with us and sat at the table, she had one or two suggestions of programs I already knew about and weren't really right for Gina. It was basically a complete bust, which, given everything else they do at that high school, I was kind of shocked. It's like, wow, this is just like a low level of service they're providing.

Mark's mother found that little that had been set forth in the transition plan was implemented, stating that there

**Table 2** College experiences of young adults with ASD: Themes and subthemes

Preparation beyond academics	
Importance of a robust high school transition process (e.g., competent high school transition staff and services, meaningful student participation in IEPs during high school)	
Need to address ASD-associated challenges prior to transition (e.g., social deficits, mental health concerns) and realistically evaluate student readiness at transition (e.g., maturity, self-regulation, independence)	
Need to address young adult stress at transition (e.g., awareness of potential young adult distress as transition approaches; preparing youth through campus tours, summer pre-college experience)	
Student/college fit	
Campus size (small vs. large), location (near vs. far), and culture	
Institutional flexibility and easing in (accepting of difference vs. not; flexible vs. rigid in its practices—e.g., making part-time load more possible)	
Campus supports	
Disability support: benefits (offer note takers, extra time on tests)	
Disability support: limits (independence, self-advocacy required in order to access DSS services and follow through with communicating accommodations to professors or reaching out for help of any kind, including mental health issues; no help for major ASD-associated challenges, including social deficits and "narrow interests")	
Additional supports (private or offered by college for extra fee) sometimes helpful	
Family supports	
Parent direct intervention (e.g., waking students for class, driving students to campus, helping organize materials, helping with registration, tutoring)	
Parent emotional support (especially for students in psychological distress)	
Limits: what parents can do, what young adults will accept	

has been an entire discussion about her son applying for VR services to aid with employment or college, but “nothing was ever done.” Such a lack could have negative consequences, especially if a student everyone had assumed was college bound didn’t end up staying on a college path. For example, Cameron’s thorough plan meant he was already connected with VR services and ready to try employment when college didn’t work out; for Mark, there was no such back-up plan in place.

#### *Need to Address ASD-Associated Challenges Prior to Transition*

Participants frequently noted that an overemphasis on academic performance in high school was detrimental to intellectually able students with ASD. This cost them in two ways. First, social-communication deficits, EF issues, mental health concerns, a lack of life skills, and other challenges were not being sufficiently addressed during the high school years. Second, these same issues were not being realistically evaluated at transition.

Daniel had only a 504 Plan in high school. His mother lamented that the school hadn’t seen her son as having any needs because of his good grades, saying that he ended up “trying college without really any idea from the high school about how to do college.” Ryan had an IEP and an expensive private placement paid for by the school district. Nevertheless, his father said the school hadn’t helped him and his wife understand what his son’s social deficits would mean, long term. Focused on their son’s 3.8 GPA, they had thought these were a “smaller issue” and so “went with the flow” rather than seeking additional interventions or changing expectations:

They do not tell you that the dream is not necessarily going to be fulfilled where he goes to college and he graduates college and he gets a job and becomes a member of society... Instead of being honest and saying that this is what you are into for the next forty years of your life; they are like, well, you should look into this or you should do this. No one ever mentioned SSI [Social Security Income] or any of that stuff.

Regrettably, planning for life post-graduation often seemed to proceed without acknowledging the full extent of a young adult’s immaturity, social struggles, or mental health concerns. Gina, who could have extreme “episodes of anger...going zero to 60 in her moods and yelling and hitting,” had attended a high school for emotionally disturbed (ED) students. Her mother described the “collective fantasy” she, her parents, and the school fell into as the end of high school approached:

They said, ‘She’s such a bright girl, and when she’s calm, she’s so terrific, and she loves to learn, and she writes beautiful papers.’ And...if you just look at her on paper, she’s like an A– minus average...

Celebrating academic success while ignoring other issues sometimes led to failure at college, as will be discussed.

#### *Need to Address Young Adult Stress at Transition*

An insistence on sameness and adherence to routine are often part of ASD (American Psychiatric Association 2013). It is therefore not surprising that some young adults, especially those with co-occurring anxiety or other mental health concerns, experienced distress as graduation approached. Said Lisa’s mother:

She was terrified... Coming to the end of high school there is this vast unknown. She was like ‘Everything is regimented - what do I do now?’... She did not know what to do. Her piano teacher noticed that her playing became very erratic... She started becoming very violent...She would hit me if she were angry. She would threaten me. She would take knives and threaten herself...

Mark shared that he was definitely unnerved by the prospect of high school’s end, saying that for him change was like “there’s a giant meteorite 5 min from hitting the earth.” He described how his behavior sometimes deteriorated during his senior year of high school:

I was having panic attacks probably at least every other day, sometimes in class. They did not know how to handle that... Usually I did not overturn desks...it generally would result in me...yelling some, flailing around, banging my fists on the desk and then...either running out of the room with more yelling or crawling underneath the desk...and crying softly, which, I mean, you know, if a senior in high school is under the desk sobbing...

One way some parents tried to diminish student fears over the transition was to familiarize their son or daughter with college, going on campus tours or arranging for some type of pre-college experience. For example, Beth’s mother found the unique pre-college summer program for students with disabilities at the local community college valuable. Beth was able to visit several college campuses, spend extended time on the community college campus, learn self-advocacy skills, and become familiar with how students interact with a college Disability Support Services (DSS) office. By the time Beth attended that same community college, she was comfortable navigating the campus.

## Student/College Fit

Whether a college was a good match for a student played a critical part in that student's experience. For students who were sometimes lagging behind their typical peers in terms of social competence, maturity, and independence, attending a postsecondary school that was smaller, closer to home, and had a quirky and accepting culture often worked better than attending a large, distant university that was less accepting of difference and more rigid in its practices.

### *Campus Size, Location, and Culture*

Sean, a bright student who struggled with anxiety and depression, applied to ten 4-year schools but decided on one that was both close to home and his therapists. At the time of his mother's interview, he was enrolled and doing well. Lori had thrived at a small, private undergraduate school only a couple of hours from home—far enough, her mother shared, to give her some independence but close enough that her parents could get to her if anything went wrong. Lori said that her college had a wonderful creative writing program and was “very small and picturesque.” She had fallen in love with it during the college visit stage. Her mother recalled how she had quickly found a “funky, eccentric group of friends” and was happier on that campus than she had ever been in her life.

David completed a Bachelor's degree at a 4-year state university located only 20 min from his home. His mother had feared he wouldn't be able to get in, and that if he did, his peers would not accept him. She confided:

But that college is pretty weird. I mean the students are very eccentric. I even talked to somebody, one of the administrators that I had met... and I said, ‘He's kind of odd’ and he's like ‘They are all odd here; he'll be fine. Have him apply.’ And sure enough—he got in.

### *Institutional Flexibility and Easing In*

Community colleges were generally more flexible than larger schools, and students with ASD often benefitted from this. Because costs were low, concerns like having to take a full load to keep financial aid were less—an important point considering that a number of students with ASD felt they could not cope with four or five classes at a time, especially not to start. Mark, a 22-year-old with an Asperger's diagnosis, was in his third year but still taking only two courses a semester. Said his mother, “He wanted to take three but he could not even handle

looking at the catalog...” She went on to explain how his anxiety interfered with his first college class:

As they did their first class she [the professor] was rattling off the rules: ‘No gum chewing; you may not leave the class before the end; you may not be late more than two times or you fail the class; there is no eating in this classroom.’ So my son is immediately thinking—it was a three-hour class—‘Oh my God, what if I need to pee? It is going to be the end of the world. Oh my God, if I cannot eat I am going to die!’ So instead of asking her questions, he is just in his mind freaking out.... By the second class, about half-way through the class, he literally ran screaming from the class.

At 4-year schools full-time loads were also usually required to live in university housing. Therefore, students who realized they had taken on too much could be trapped by both financial aid and housing provisions. Harry, an 18 year old freshman feeling overwhelmed at a large, private university thousands of miles from home, dropped some classes to take the pressure off only to find that he was then asked to leave the dorm. His parents were forced to scramble to find him an apartment on short notice.

## Campus Supports

Community colleges and universities offer an array of supports for students, from academic advising to career planning. For students with disabilities, there is typically a DSS office that arranges accommodations such as extended time on tests or a note taker. These are roughly equivalent to what students with 504 Plans receive in the public schools, and fall far short of the extensive assistance a student with an IEP may have received. Some families were satisfied with what DSS provided, while others were not.

### *Disability Support: Benefits*

Beth's mother declared the assistance provided at her daughter's community college invaluable:

They have a great support system. She has a disabilities service counselor who's fabulous. I can't say enough about how helpful she's been. They let the kids with disabilities register early, so she never has any problems getting classes. Phenomenal support. Even though it's not called an IEP, she has an accommodations letter. They kind of take it to the next step where she's responsible for taking that letter to her professors and walking it through. The professors have all been amazing.

Sean's mother also found the DSS office on his 4-year campus very helpful:

He was insistent that he had to be able to live on campus. So we again talked to people at...DSS. They looked at all of his paperwork and they said 'Well, we need to approve you for a single because you clearly are going to meet with success if you do not have to deal with a roommate. You know, you will have a suite-mate on the other side, but you will not have a roommate.' Sean was like 'That is what I was thinking! Thank you very much.'

#### *Disability Support: Limits*

As Gina's mother was warned during a campus tour, for some students with ASD what DSS has to offer is not enough:

This very nice woman there, who runs the special needs support, she said, 'Kids who come here, even though it's those with special needs, have to really be able to get up every day, get to class. They have to be able to take their meds. They have to be able to do their homework. We are here to help them, but they have to also be able to come to us and get the help they need...If they're behind and they haven't told anybody, they get more and more behind to the point that they're ashamed and embarrassed and afraid...'

Mark's mother noted just such an issue regarding her son's inability to follow through and benefit from the help offered by DSS.

The difference between college and high school was they offer a certain level of support but they are only supports that you are willing to self-advocate for. For example... the counselor worked out his accommodations... That paper, once it was complete, he needed to come back to the office and pick it up. He needed several copies... It was his responsibility to give it to each of his professors. He needed to arrange with each professor for a meeting. These were things that, again, for a kid like him with these missing social contexts, it just was not happening.

Daniel's mother reported similar problems, distraught that she couldn't make her son take advantage of the help available.

Yeah. They have that support. They said that they can give you a tutor, you can go to talk to them, but he doesn't want to talk to them, and he doesn't want to get a tutor. The problem is that he has to initiate this thing, he has to walk to the disability department to talk to them, but he didn't. I think that maybe he

thinks it doesn't help him. Or he just gets stuck. He doesn't want to think of other ways to solve the problem. He just totally gets stuck and then shuts down.

Daniel also had difficulty caring about courses that were required but not connected to his passionate interests—a motivational issue mentioned by a number of parents and one DSS could do little about.

#### *Additional Supports*

A number of families, recognizing the need for additional supports, arranged for these. Some of the programs accessed were purely private; some were offered through the college itself; and others were sponsored by a VR agency serving transitioning youth with disabilities. Except for the last, these generally involved paying a substantial amount of money in addition to regular tuition and fees. Services ranged from tutoring to assisting with apartment living and social needs.

Parents also directly hired tutors and peer mentors, with varying degrees of success. Finding someone who was familiar with ASD and able to address a student's needs was a challenge. The first peer mentor Harry's mother tried to arrange stopped showing up without notice. The second was not much better:

We finally hired... somebody else, a guy. He liked hanging out with Harry and Harry liked him and he's a cool dude and all of that, but he's not a peer mentor. He never did any activities with him. He never went on the camping trips that he was supposed to go on. He never accompanied him to any activities. He accompanied him to one activity, arrived an hour late, and left after 20 min. So...that's not what we were hoping for.

#### **Family Supports**

##### *Parent Direct Intervention*

While some students were fairly independent at the beginning of college, others needed more support. Families provided all kinds of assistance to their young adults with ASD, from the practical to the emotional. At the risk of being labeled a "helicopter parent," many did whatever they felt was necessary in the belief that their son or daughter needed this extra support to grow, adapt, and succeed at college. David's mother called his dorm room to wake him up every day the first year, driving to campus to physically rouse him if he didn't answer. By the second year, he was waking on his own. Three years into community college, Mark's mother reported he was beginning to be able to handle the registration process independently:

This semester he is looking at things by himself and he is ‘I can’t believe I am doing this, I am registering by myself!’ He has not finished, he has only signed up for one class so far, but he did all of it... He went through that complicated, convoluted registration process, and he has done it by himself.

### *Parent Emotional Support*

Understandably, pre-existing mental health issues were a worry for many. Sean’s mother provided emotional support by phone and text:

He will not do well on one test where he thought he had studied. And then it cycles, and cycles, and cycles and then all of a sudden he is on the phone with me, and he is like ‘I just have to drop out of college,’ and ‘life is not worth living.’ And I am like ‘Okay, sounds like we have hit bottom, ready to turn back around...’ His ability to manage these episodes is improving, but the episodes still happen, and as a parent, that is always really scary.

### *Limits: What Parents Can Do, What Young Adults Will Accept*

Of course, young people do not always desire their parents’ help. Cameron’s father explained that his attempts to assist with “executive function stuff” were rebuffed:

He just could not organize things even with all the support to the point where I think he ended up failing everything. And he’s always very resistant to get help from us. So whenever we would try to help him organize binders and calendars and those kind of things he just didn’t want help from us... So that first semester I think he took two or three classes and he ended up failing.

Parents often found they could do little to assist with the social aspects of college life. Billy, who was driven daily to a nearby private 4-year school, enjoyed his coursework and class discussions but graduated without forming any lasting relationships. Said Billy matter-of-factly:

In high school, over four years, you get to know a person, what makes them tick, their good sides, and their not so great sides, whereas in college, in my experience, in the 16 weeks of a semester, two times a week, you may not get to know people but you were friendly with them. At the end of the semester, it dissolved, because you do not have anything in common anymore.

His mother regretted that no meaningful social relationships developed, though she was not sure if her son felt the same way. She said:

He liked college, and he got in, and he went. He probably didn’t have more than a couple of minutes of conversation with anybody. But he got good grades and he graduated with honors.

### **Crises at College: A Reflection of Key Themes**

In two (11%) cases, a young adult who had not been terribly motivated dropped out of community college, one to work in a hobby store and the other at a grocery store. Both were living at home, and neither expressed much distress about this. In contrast, five (28%) young adults were living on or near campus when they suffered a crisis. Four were at a distant 4-year university when this occurred, while the other was at a 2-year college living in dorms through a private support program. Their experiences underscore previously discussed themes, including the need to address non-academic deficits during high school and the importance of choosing a college that is a good match for a student’s capabilities.

Gary, who left home for a distant 4-year college, wanted to be in a military-focused program that was premised on the formation of intense social bonds. He also had a learning disability, and math was difficult for him. He quickly began to fail socially, on the one hand, and academically, on the other. Returning from the winter break, he discovered he was on academic probation.

By two weeks into the second semester, I just broke down, quit one day, and two days later I am contemplating suicide... I called my family. I went to just the counseling staff they had on campus. At that point, fortunately, there were some local family members there that I could talk to and stayed with them until my mom came and got me back. We just went back home.

Fortunately, Gary did recover, graduating from a smaller college closer to home.

Daniel’s mother explained how guilty she felt that she couldn’t somehow make college work out for her son. She wept as she told his story:

He didn’t say anything. He just didn’t go to class, didn’t take exams. Then I asked him what was wrong. He didn’t tell us. He said ‘everything is fine’ until the end. We found out anyway. He was just lying. He just tried to cover it up. I asked him. He said, ‘I just don’t feel good. I feel depressed. I don’t feel as though my life can continue. I even want to kill myself.’



Daniel eventually enrolled in a different 4-year school, this time near his hometown, though he continued to struggle.

Ryan's father was visibly upset as he related the brief duration, after all the college applications and preparation, of his son's time on campus:

He lasted 68 days. He was able to stay current at C-level in his work... He never went to the dining hall once. He could not handle the dining hall, he could not handle the noise, he could not handle the whole thing. He would go to Target once a week on the University shuttle bus and get Pepsi and Goldfish crackers, and that is how he lived for 68 days.

After returning home, his father said, Ryan was "wrecked." He had always known he was "different" and had "barriers," but had never before felt "stupid or out of place."

Gina's mom, recognizing that her daughter was not ready for college, had encouraged her to take a "gap year" after high school graduation. Even with this extra time, and the added assistance of a private disability support program, Gina was unable to overcome her many challenges.

She basically completely crashed, and we didn't even really have until the spring. She went to class and kind of muddled her way through, but she wound up dropping one class in the fall and then basically failing the other one... Academics was just like the tip of the iceberg....She was getting into verbal and physical altercations with other kids and hitting them. She did get involved in a sexual relationship with another young man in the program. From there it really spiraled.... We brought her home.

Harry, a freshman at a large university, went into crisis when a girl he thought had become his friend wearied of his company and cut him off saying she didn't want to have to "babysit him." He ended up in the hospital, his mother flying to get to him as fast as she could. According to his mother, Harry was crying: "Mom, I'm so sorry. I'm terrible. I'm a bad son. I'm a bad person." She fought to salvage the situation, but found the university administration unsympathetic.

These women, these two really angry, not angry—that's not the right word, they were very cold—said 'Harry, it looks like you're not happy here. I looked at your grades and you're not doing particularly well this first semester.... Do you really want to stay here or not?' and Harry, who's put on the spot, says 'No, I want to go home.' 'Great. So here is the form so you can unenroll...'

## Discussion

Eighteen families of young adults with ASD shared their experiences surrounding postsecondary education. Common themes emerged, including the importance of addressing nonacademic areas of weakness during high school; the value of student/college fit; the lack of ASD-specific support on campus; and the importance and limits of family-provided support.

Participants' narratives suggest that outcomes were better for college students with ASD when high schools and families addressed, long before graduation, social, EF, and other ASD-associated challenges. Unfortunately, schools often minimized nonacademic issues, viewing a high GPA as a guarantee of college success. As noted by Hedges et al. (2014), "In an era of accountability based on high stakes testing, the primary focus of educators tends to be on increasing academic achievement. For students with ASD, the trickier aspects of social life...may go unaddressed or overlooked..." (p. 66). Reassured by high grades and test scores, hopeful parents could also downplay nonacademic deficits. Ignoring gaps in coping, social, or EF skills was ill advised, particularly when extensive supports had facilitated high school accomplishments. Equivalent supports were unlikely to follow the student to college.

A realistic assessment of academic and nonacademic abilities was also necessary to match students to a college where they could be successful. Students who were less mature or independent, had acute social challenges, or struggled with depression or anxiety, seemed to fare better on a smaller campus closer to home, with access to parents, longtime friends, and therapists. A reduced course load was sometimes helpful, relieving pressure as a student adapted to a new environment and routine. Finding a campus accepting of difference was also important.

Most students were able to access general DSS accommodations. ASD-specific supports, however, such as assistance navigating the social aspects of campus life, were often lacking. Institutions with capable, welcoming, flexible DSS and other staff were of course a better fit, but it was also important that young adults had been taught to self-advocate so they could make use of offered supports. In most cases, families provided a great deal of practical and emotional assistance. Some parents drove a student to campus daily or helped with organizing study materials. Others lent frequent encouragement over the phone or intervened with the administration when problems arose. There were limits to what families could do, however, especially in the social realm.

Based on the experiences of these young people and their families, it is evident that not all diploma-capable high school students with ASD are ready for college at 18. Pushing them to graduate with their typical peers may be

doing them a disservice. Alternatives are easy to imagine. Wehman et al. (2014) developed an ASD-specific program that eases high school students with intellectual disability into the world of work. A parallel program for the college-bound could be developed, permitting these vulnerable students to remain under the protection of IDEA a year or two longer, meanwhile taking community college courses and addressing areas of weakness (e.g., social deficits, EF). Another possibility is participation in summer programs that provide a pre-college experience tailored to the needs of high school students with ASD (Retherford and Schreiber 2015; Howard Community College 2017). Clearly, there is an urgent need to evaluate routine practices at transition and consider possible alternatives when the cost of failure is so high. From eroded self-esteem to suicidal ideation, students with ASD who stumbled at college suffered, as did their families.

The study has a number of strengths. First, it addresses a gap in the literature. Broad recruitment criteria and open-ended questions made it possible to capture information about not only students with ASD who were succeeding at college, but those who failed. Second, it makes explicit a rarely explored link between high school practices and college outcomes for this group. Third, the perspectives of seven young adults with ASD were included in this analysis, insuring voices of the group under discussion were heard.

### Limitations

This study has a number of limitations. It utilized a small convenience sample of 18 families from the mid-Atlantic region. In addition to being served by a limited number of school districts and local agencies, these families were mostly white and occupied high income brackets. Results are therefore not generalizable. ASD diagnoses were based on parent report and not confirmed by medical records or in-clinic assessments. While at least one parent from each family participated, only seven young adults were both available and willing to be interviewed, limiting the number of young adult voices included in this analysis.

### Conclusion

Many young adults with ASD are cognitively able, even gifted, and can succeed at college with adequate preparation and support. It is important that high schools, families, and institutions of higher education collaborate to maximize the likelihood of success for these students. Particularly important is addressing key challenges during the high school years, refusing to let academic achievement blind supporters to areas of weakness such as social deficits,

EF issues, or anxiety. Also key is carefully matching first college experience to readiness in terms of maturity and independence while recognizing that the accommodations provided by a typical DSS Office may need to be supplemented with ASD-specific support. Future research should utilize larger and more diverse samples to investigate which high school and college practices, policies, and programs are associated with success for postsecondary students on the autism spectrum.

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### Compliance with Ethical Standards

**Conflict of interest** The Authors declare that they have no conflict of interest.

**Ethical 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. This article does not contain any studies with animals performed by any of the authors.

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

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