Academic experiences for college students with autism: Identity, disclosure, and accommodations.


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A large and fast-growing population of individuals with Autism Spectrum Disorders (ASD)—a neurodevelopmental disorder characterized by impairment in social communication and the presence of restricted and repetitive behaviors (American Psychiatric Association, 2013)—are completing high school with reasonable expectations for continuing on to postsecondary education. The nascent body of literature on individuals with ASD in postsecondary education, however, is discouraging. Only 34.7% of individuals with ASD even attempt college within 6 years of leaving high school (Shattuck et al., 2012). Once in college, students with ASD face daunting social, emotional, independent-living, self-advocacy, and communication challenges both inside and outside of the classroom (Adreon & Durocher, 2007; Gobbo & Shmulsky, 2013). Moreover, critical holes in the empirical literature currently make it impossible to develop large-scale, evidence-based, and empirically-validated interventions for college-going adults with ASD.

The current study begins to fill these knowledge gaps by (1) defining salient issues affecting college success for individuals with Autism Spectrum Disorders; (2) uncovering potential points of intervention; and (3) identifying prominent features of existing interventions that promote college success for students with ASD. The primary research question for this study is: How do adults with an Autism Spectrum Disorder make sense of and respond to autism-specific barriers to postsecondary success? Drawing data from in-person interviews of adults with ASD who have attended college, this study gives voice to an often-overlooked population of college students and highlights opportunities to improve postsecondary experiences for students with ASD.

**Background and Context**

**Growth of ASD in College**
Estimates from 2011–2012 show that approximately 1 in 50 children ages 6–17 have Autism Spectrum Disorder (ASD) (Blumberg et al., 2013). Since 2007, the prevalence of ASD diagnoses has increased across all ages, with the greatest relative increases in older children, ages 14–17. Autism Speaks (2012) estimates that “approximately 50,000 individuals with ASD turn 18 each year in the United States” (p. 1), an age typical of graduating high school students. Many of these students are now graduating from high school and have reasonable expectations for access to and success in postsecondary education (Camarena & Sarigiani, 2009; Chiang, Cheung, Hickson, Xiang, & Tsai, 2012). After reviewing the literature on the postsecondary pathway for ASD students, Zeedyk, Tipton, and Blacher (2014) conclude that ASD has increased in prevalence in recent years, both in the general population and on college campuses. In the only published study of its kind, White, Ollendick, and Bray (2011) study suggests that “between 0.7 percent and 1.9 percent of college students could meet criteria” (p. 683) for an autism spectrum disorder.

However, research indicates people on the autism spectrum have poor postsecondary attendance patterns and outcomes (Glennon, 2001), even when compared to other students with disabilities (Wei, Yu, Shattuck, McCracken, & Blackorby, 2013). One recent study (Shattuck et al., 2012) reports that only 34.7% of individuals with ASD attend postsecondary institutions within 6 years of leaving high school—a span of time that is considered 150% of the rate typically expected for completing a bachelor’s degree. This situation is unfortunate, as many individuals with ASD achieve academically at the same or higher levels than their typical peers, and would likely succeed in college with appropriate support (VanBergeijk, Klin, & Volkmar, 2008). To support this population of students, colleges and universities must be able to first identify them. However, many students may either enter college undiagnosed (White et al., 2011) or choose not to self-identify to a disability resource office (Van Hees, Moyson, &
Thus, supporting the needs of this growing population is a “considerable challenge for which we may be ill-prepared” (White et al., 2011, p. 697).

Considering these statistics and the growing need for interventions and support for students with ASD, the current body of literature on individuals with ASD within postsecondary education leaves much to be desired. Once in college, students with ASD face daunting social, emotional, independent-living, self-advocacy, and communication challenges both inside and outside of the classroom (Adreon & Durocher, 2007; Gobbo & Shmulsky, 2013). While the extant literature has tracked basic entry and completion rates for this population, far less is currently known about these students’ experiences while enrolled in institutions of higher education. Such critical holes in the empirical literature currently make it impossible to develop large-scale, evidence-based, and empirically-validated interventions for college-going adults with ASD.

Our own review of the literature revealed no indication that college faculty and staff are being adequately trained to support this population’s needs. White et al. (2011) argue the importance of screening college students for autism, as many students may meet criteria for ASD symptoms but have never been diagnosed. The first step to being prepared for the forthcoming influx of autistic students lies in awareness and knowledge about ASD for faculty, staff, administrators, and students at our institutions (Tipton & Blacher; 2014; VanBergeijk et al., 2008).

College Challenges and Supports for ASD Students

A small but growing body of research has focused on intervention programs addressing students’ transitional experiences from secondary to postsecondary education (Hendricks & Wehman,
2009; Papay & Bambara, 2011; Roberts, 2010; Zager & Alpern, 2010). Zager and Alpern’s (2010) Campus-Based Inclusion Model (CBIM) focuses on the development of social communication skills for transition-aged students with ASD. Under the CBIM, students with ASD enrolled in high school attend classes on a college campus that “provide a positive, age-appropriate postsecondary option that will prepare them for adult living” (Zager & Alpern, 2010, p. 153). While preliminary results of a small pilot study indicated positive results, the study neglects to demonstrate whether participation in a CBIM program contributes to greater success at the postsecondary level, higher enrollment or persistence at an institution of higher education, or greater job success and satisfaction. Similarly, Papay and Bambara (2011) survey 87 postsecondary education (PSE) programs for students with intellectual and other developmental disabilities. However, their survey neglects to detail the students’ experiences within these programs or provide information about student enrollment in postsecondary education due to the PSE program.

While the transition into college is a critical period for ASD students, the literature thus far has provided little evidence documenting the success of these transition programs and largely fails to discuss the lived experiences of students. Moreover, because institutional interventions on the part of postsecondary institutions are still in their infancy, conclusions about outcomes for participating autistic students are difficult to identify. Barnhill’s (2014) survey of 30 institutions of higher education that offer specific support services for students with Asperger’s Syndrome (AS) and high functioning autism (HFA) reveals that very few institutions have any data on student outcomes, as more than half of the programs surveyed provided services for fewer than five years. The institutions surveyed, however, indicated that institutional efforts to support these students should be both flexible and comprehensive (Barnhill, 2014). Although programming for
transition-age students with ASD has become more accessible, these programs often do not provide students with the specific resources or services they need. As a result, students and their families experience a breach between their aspirations and goals and the reality of resources that are available in transition (Zager & Alpern, 2010). This gap between what is necessary and what is known about student outcomes demarks a critical hole in the nascent body of literature.

Perhaps as a result of theoretical or empirical literature on postsecondary students with autism, the rapidly growing number of well-intentioned and face-valid interventions for college students with ASD (e.g., Gobbo & Shmulsky, 2012; Pugliese & White, 2013; Zager & Alpern, 2010) are based largely on generalizations derived from the literature on ASD in children or the K–12 educational environment (e.g., de Bruin, Deppeler, Moore, & Diamond, 2013; Eldevik et al., 2009; Reichow, 2012). Many such postsecondary interventions (Pennsylvania Autism Services Education, Resource, Training Collaborative, 2012) and much of the literature advocating for such interventions (e.g., Adreon & Durocher, 2007; Glennon & Marks, 2010; Vanbergeijk et al., 2008), address the social needs of students with ASD, including adjustments to independent living or living with roommates, budgeting, social life, and dating (Gobbo & Shmulsky, 2013). Often overlooked are the classroom behaviors (such as the inability to understand peer and instructor nonverbal cues and trouble with group work), cognitive difficulties (such as difficulty writing or presenting to an imagined audience and the inability to link concepts abstractly), and comorbid conditions (such as anxiety) (Gobbo & Shmulsky, 2013; Wenzel & Rowley, 2010) that may undermine college success for students with ASD.

**Autistic Student Voices**

While some researchers have speculated about specific intervention and support needs of this population (e.g. VanBergeijk et al., 2008; Roberts, 2010) and others have observed the
perspectives of faculty (Gobbo & Shmulsky, 2014), peers (Nevill & White, 2011; Westling, 2013), and parents (Clark 2013; Griffin, McMillan, & Hodapp, 2010), researchers have collectively failed to validate these observations with the lived experiences of students with ASD. Van Hees, Moison, & Roeyers’ (2014) study is unique in that it attempts to understand the college experience from the perspective of students with ASD. Through qualitative methods, the researchers gather a better understanding of the needs of these students and their transitional, educational, psychological, and social challenges they face. Furthermore, the authors are able to make specific, tailored recommendations based on these lived experiences. One strength of this study is that first-person accounts allow for insight into the ways in which students with ASD process information and understand their own college and university experiences. Gelbar, Smith, and Reichow’s (2014) literature review suggests a lack of research on these students’ experiences and suggests further research be conducted to describe firsthand accounts of college students with ASD. The present study heeds that suggestion and draws from first-person accounts of the lived experiences of students with ASD.

Collectively, the current body of research documents a growing population of autistic students with access to postsecondary education, but provides little understanding of their experiences once in college. The literature also reveals poor postsecondary outcomes for students with ASD, confirms the absence of evidence-based treatments for these students, and highlights critical holes in the empirical literature. Such gaps undermine nascent efforts to develop educational interventions that improve postsecondary access, experiences, and outcomes for students with ASD. This study begins to fill these knowledge gaps and starts to pave the way to subsequent development of scalable, efficient, and effective interventions that facilitate
successful transitions into, through, and out of higher education for students on the autism spectrum.

**Conceptual Framework**

Decades of research have supported theories that a lack of academic and social integration (Tinto, 1993), engagement (Kuh, 2003), or involvement (Astin, 1993), can undermine a student’s chances at postsecondary success. Indeed, studies of college student success are often framed by conceptual models reflecting the three elements of Astin’s (1991) Inputs, Environments, and Outcomes (I-E-O) model. Although the I-E-O model is most often applied to the study of “traditional” students, the model can be applied to college students with disabilities (O’Neill, Markward, & French, 2012).

Therefore, we use Astin’s (1991) Input-Environment-Output (I-E-O) model to organize the primary topics discussed in interviews. Table 1 outlines the topics discussed in the interviews clustered around their respective I-E-O categorization. The Inputs reflect issues that might impair students' consideration of, aspirations for, or access to postsecondary education. The Environments (or Experiences) include college-specific issues that could derail a student after college entry and that are of heightened concern for students with ASD. The items listed as Outcomes represent four broad categories/measures of student success in college toward which researchers could target subsequent interventions.
Table 1. Adaptation of Astin’s I-E-O Model for study of Autistic Students

Inputs
- student perceptions of postsecondary opportunities
- access to college-going knowledge (e.g., deadlines, application requirements)
- aspirations/expectations for life after K–12
- destinations (institutions and majors) for those with ASD who attend college
- fears/concerns about going to college

Environments/Experiences
- social interactions with peers
- interactions with faculty members
- courses/academics
- self-disclosure/advocacy
- use of student support services (both general services and those specific to ASD/disability)
- self-management/life skills
- mental health and co-morbid conditions (e.g., anxiety, depression, ADHD)

Outcomes
- postsecondary credentials: degree/certificate completion
- academic success/learning: grades, credit hours, content knowledge, academic skills (e.g., critical thinking, analytic reasoning)
- psychosocial/practical development: self-management, life skills, interpersonal skills, emotional control
- post-college: graduate school, career readiness, employment (meaningful, continuous employment with a livable wage)

Methods

Population and Sample

The population of interest consists of individuals who have been formally diagnosed with Autism Spectrum Disorders who are attending, have attended, or may be eligible for postsecondary education. For simplicity, the population can be broken into four categories of adults with ASD as they relate to postsecondary education: (1) “Non-Starters,” who have not yet attempted college; (2) “Current Students,” who are currently enrolled in college; (3) “Departures,” who attended a postsecondary institution but left before completing their degree; and (4) “Completers,” who completed college and earned a postsecondary credential. Because recent data suggest that students with ASD tend to begin at two-year colleges (Wei, Christiano,
Yu, Blackorby, Shattuck, & Newman, 2013), and reflecting the language used by the Institute of Education Sciences, we consider postsecondary enrollment to include any course of study “leading to a formal certification or degree (associate’s or bachelor’s).”

The sampling frame for the study included at least 118 adults with a formal ASD diagnosis and have registered with the local Center for Autism and Related Disabilities (CARD), a state-funded office providing free support and resources to individuals with autism. The Center distributed flyers and emails to eligible individuals and mentioned the study as appropriate when meeting with clients. However, recruitment of willing participants proved exceptionally difficult. Consistent with the ethical and legal considerations, and as approved by Florida State University’s Institutional Review Board, the researchers did not have direct access to the names or contact information for local students diagnosed with ASD, severely restricting the ability to do follow-up recruitment emails, calls, or letters. In part because of these constraints, only nine students agreed to participate in the study. Of those nine, one student (Adam) joined the study after being invited to do so after revealing his diagnosis to one of this paper’s authors who happened to part of the same PhD program. Another participant (Isabel) was a rising high school
senior who would be applying to college in the months following her interview. See Table 2 for brief profiles of each of the study’s participants.

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age</th>
<th>Gender</th>
<th>ASD diagnosis</th>
<th>Co-morbidities/age of diagnosis</th>
<th>Highest Degree</th>
<th>Current Educational Status</th>
<th>Current Vocational Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adam</td>
<td>30+</td>
<td>Male</td>
<td>3</td>
<td>Bipolar (Age 20)</td>
<td>Bachelor of Science</td>
<td>Graduate School</td>
<td>Employed</td>
</tr>
<tr>
<td>Brian</td>
<td>50+</td>
<td>Male</td>
<td>In his 40s</td>
<td>ADDHT, Dyslexia (childhood)</td>
<td>High School</td>
<td>Technical School</td>
<td>N/A</td>
</tr>
<tr>
<td>Christopher</td>
<td>24</td>
<td>Male</td>
<td>8 or 9</td>
<td></td>
<td>Bachelor of Science</td>
<td>N/A</td>
<td>Employed</td>
</tr>
<tr>
<td>Daniel</td>
<td>20+</td>
<td>Female</td>
<td>9</td>
<td></td>
<td>High School</td>
<td>Community College</td>
<td>N/A</td>
</tr>
<tr>
<td>Edmund</td>
<td>21</td>
<td>Male</td>
<td>15 or 16</td>
<td></td>
<td>GED</td>
<td>Community College</td>
<td>N/A</td>
</tr>
<tr>
<td>Franklin</td>
<td>23</td>
<td>Male</td>
<td>Unknown</td>
<td></td>
<td>High school</td>
<td>Community College</td>
<td>Volunteer</td>
</tr>
<tr>
<td>Gregg</td>
<td>33</td>
<td>Male</td>
<td>26</td>
<td>ADHD (Age 9)</td>
<td>Bachelor of Science</td>
<td>N/A</td>
<td>Employed</td>
</tr>
<tr>
<td>Harper</td>
<td>19</td>
<td>Male</td>
<td>Unknown</td>
<td></td>
<td>GED</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Isabel</td>
<td>18</td>
<td>Female</td>
<td>4 or 5</td>
<td>ADHD, Dyslexia</td>
<td>N/A</td>
<td>High School</td>
<td>N/A</td>
</tr>
</tbody>
</table>

Note. All names are pseudonyms to protect privacy.

**Setting and Procedures**

Semi-structured interviews (Fetterman, 1998) were completed at a location familiar to each of the study participants. All interviews were conducted in person, one-on-one, by the lead author, with the exception of Adam’s interview in which his classmate sat in on the interview at Adam’s request. Interviews centered upon student inputs, experiences, and outcomes in higher education (Astin, 1991) as outlined in Table 1. For example, participants were asked to describe their initial fears about going to college, their decisions about whether and when to disclose their ASD diagnosis, and their development of academic, social, and independent-living skills. Throughout, participants were asked to provide examples of “critical incidents” that shaped their college expectations, experiences, and outcomes.
Eight of the nine interviews were video recorded; Adam’s interview was recorded with audio only, at his request. Each interview was professionally transcribed, with recordings and transcripts time-synched to allow coding of the transcripts while simultaneously viewing of the interview. Because individuals with autism often have difficulty with verbal communication, the video recordings are particularly important; nonverbal cues augment written transcripts to allow a more nuanced and comprehensive understanding of participants’ responses.

**Data Analyses**

Analyses proceeded using a constant comparative approach (Straus & Corbin, 1998) whereby data collection and analyses are conducted iteratively, with concepts from previous interviews explicitly explored in subsequent interviews. For example, because each of the first two interviewees made specific mention of online or computer-based postsecondary programs, each of the remaining participants was asked specifically about experiences with computer mediated coursework. Coding of data from each interview has proceeded through a two-step process.

First, two of this paper’s authors used the I-E-O framework outlined in Table 1 as an a-priori descriptive coding structure. The two round-one coders had previously employed the same coding structure to transcripts from online discussion forums for individuals with autism during which the coders underwent several rounds of coding the same data and subsequently meeting to reconcile any disagreements in coding. The round-one coders also wrote reflective memos and created in-vivo codes as they recognized patterns of interview segments that did not fit into the a-priori coding structure.

The second round of coding was conducted by the lead author (who also conducted the actual interviews) and focused exclusively on the “experience” codes. In this phase, instead of reviewing the individual transcripts, the lead author examined all of the instances – across all
nine participants – which were coded in the same way. Thus, for example, all interview segments which were initially coded as “Experience – Disclosure” were reviewed separately from those segments first coded as “Experience – Peer Interaction.” During and immediately after review of each code-specific report (ranging from 16 – 46 pages each), the lead author highlighted report text and wrote memos noting recurring phenomena, representative summary statements, rich or vivid phrases, and patterns of proximal statements (i.e., when statements about two topics were linked together by the participants).

The original plan for presenting results from this analysis was to present findings in clusters that paralleled the original elements of the I-E-O framework (see Table 1). However, when reviewing the transcripts and highlighted reports, the lead author recognized two patterns that disrupted those plans. First, specific sections of transcripts seemed to show up in multiple code-specific reports, suggesting that the interviewees were discussing simultaneously what the researchers had anticipated would be distinct topics. Second, and quite contrary to the expectations derived from the limited available literature on the topic, the vast majority of the coded statements related to students’ academic experiences with college instead of their social experiences. As a result, we present our findings as three code- and interview-crossing themes.

Findings

A Critical Threshold

Going to college is a major life event for all of these students, standing out as a point of demarcation in their lives. For most of the interviewed students, going to college represented a transition that sounded a lot like what one would expect to hear from a typical young adult. In the words of Christopher, “Adults go to college. Kids go to high school, middle school and elementary school. It’s really that defining moment where you’re no longer a teenager. You’re
now an adult.” Franklin was “tired of being underneath their roof” while Gregg spoke excitedly about the new opportunities for personal and social exploration suddenly available to him.

Going (back) to college was even more dramatic for Brian, who described his return to community college in the fall in terms of life and death, as a pivotal point between his history of despair and future of hope. This 50+ year-old man, who had attempted suicide on several occasions over the preceding two decades, and who had previously been kicked out of technical college before finishing even a single course, saw his re-enrollment as the catalyst for his recent perceptions of self-worth.

Brian: When I was sitting with them and they told me all that I said ‘I’m feeling suicidal.’ My world came to an end when they said ‘we’re kicking you out of school.’ I thought my world was coming to an end. They sent me to the nut house. Which was a good thing. I needed to get my stuff together. Since then I haven’t thought of suicide. I have a future. I felt better about myself than I have since I was a kid. That’s a good thing. I’m looking forward not backwards.

When reflecting on the significance of his forthcoming re-enrollment, and in a matter-of-fact way that offered no indication of hyperbole, Brian said “I hated myself for 30 years. I don’t anymore. I’m not quite to where I love myself but I like myself. That’s a big change.” Subsequently, Brian explained, “I’m excited. I will be an awesome digital artist.” Fifty years into a life filled with extraordinary challenges and disappointments, a single course at the technical college gave him hope for the future.

Focus on Academics

To the researchers’ surprise, participants discussed the college experience primarily in terms of academics, with relatively little mention of interpersonal, cultural, or independent-living challenges. In the initial round of coding, for example, there were 129 instances coded as “Academics” with only 26 coded as “Life Skills.” Although there were 143 total instances of
round-one codes for “Social,” 49 of those instances were in the “faculty-interaction” subcategory. And upon closer inspection, many of the sections coded as “peer interactions” were references to in-class activities or group assignments. Although challenges with roommates or romantic relationships were mentioned by Adam, Gregg, and Daniel, the interviewees rarely touched on these topics without explicit prompting. This focus on academics runs counter to expectations generated by the literature, and has several potential explanations.

First (the naively hopeful interpretation) these students may not have encountered many social challenges and/or overcome such challenges with such ease so as to make them not stand out as critical incidents/issues for the students in college. Second, the ASD students we have talked to may have simply managed to avoid environments and activities that require social interaction. Indeed, several students lived off-campus, avoided popular college activities/organizations, and took back-seat roles in group work when possible. A third possible explanation is that students who have reached the age and cognitive development necessary to attend college have developed (in the previous 18+ years) sufficient self-monitoring and self-regulatory skills so as to mitigate the threat of performing socially inappropriate behaviors. This explanation seems plausible at least for Adam who indicated “most of the time I try and do a lot of impression management.”

A fourth explanation is also possible, one that is almost surely true for Franklin. His mother repeatedly mentioned before the interview that he should talk about some major incident he had while at the local community college. But anytime our discussion turned toward social issues, he immediately asked for a break or quickly shut down that line of questioning. For example, about 35 minutes into the interview, and after Franklin had made reference to the first day of classes at Florida State University (FSU), the interviewer asked if he had any interest in
attending FSU, to which Franklin responded “sure” and confirmed “yeah.” The conversation that ensued was telling, both because it highlights specific concerns of his mother and because Franklin wouldn’t discuss those concerns in the interview:

Researcher: Would you go to Florida State?
Franklin: My mom would never put me on Florida States campus
Researcher: Why is that?
Franklin: Because she doesn’t think I can, would succeed on Florida States campus.
Researcher: Why is that?
Franklin: Because of, just a lot of things. It’s hard to explain.
Researcher: If you’d be willing to try, I’d try to understand, because one of the things I’m trying to do in this study is understand what we, people who work at Florida State, can do to make other colleges like Florida State more accessible for students on the autism spectrum.
Franklin: I think just maybe the safety side and also grades and stuff, my GPA and a whole bunch of other social issues and stuff.
Researcher: So grades and safety and social issues?
Franklin: Yeah
Researcher: Grades I think I understand. Safety, what is the concern about safety?
Franklin: I don’t really want to go into it.
Researcher: Okay. How about the social issues?
Franklin: I don’t want to go into that either.

Although did Franklin not want to talk about the social or safety issues that concerned his mother, his behavior during the interview offered some hints about the potential social challenges Franklin would be likely to encounter in college. Throughout the interview, Franklin’s hands were in constant motion, his eyes rarely made contact with mine, his responses to interview questions were typically 10 words or fewer, and he regularly returned to talking about a specific sports talk radio show regardless of the questions asked or where the conversation was headed. Twice we had to stop the interview so he could demonstrate the sports-radio app on his phone. If these behaviors were at all typical of his social interactions – and subtle clues from his interactions with his mother and the receptionist at the beginning and end of the interview suggest as much – Franklin surely would have difficulty navigating the unfamiliar and somewhat chaotic social landscape of typical college orientation activities, large first-year courses, group projects, or life with a roommate. Moreover, although we highlight the interview
with Franklin, six of the nine interviewed students displayed some sort of interpersonal behavior (e.g., body rocking, nose picking) that would likely be off-putting to their peers.

**Identity, Disclosure, and Accommodation**

Because the literature suggested that students with autism might be reluctant to publicly disclose their ASD diagnosis, our interview protocol included explicit questions about when, where, to whom, and how they shared their diagnosis with others. Likewise, because ASD is considered a disability that institutions must accommodate according to the provisions of the Americans with Disabilities Act, the interviews also explicitly asked the support services or accommodations used by the participants. Upon reviewing the code-specific reports, however, it became clear that the same sections of transcripts were present in both code-specific reports, suggesting that self-disclosure and the use of formal disability accommodations were not distinct issues amenable to independent consideration. Rather, these two issues were simply the outward manifestations of an internal *identity* development process that was ongoing for each student.

Although the interviewed students varied dramatically in both current age and their age with diagnosed with ASD (see Table 2), with some not receiving a formal diagnosis until after their first college experiences had ended, all of them reported some degree of awareness that they were different from their peers. As Brian put it, “I’ve known I was cross-wired for 20 years” despite not receiving his formal diagnosis until six years ago. But even after students were provided a diagnosis – enabling them to put a medically-provided formal name for their status – few of them appeared comfortable integrating their internal awareness of their condition with their outward representations of self.

Edmund’s comments about when and how to disclose his condition was representative of students’ ongoing uncertainty about the role autism played in their personal identity and daily
encounters with the rest of the world. Despite saying he was “comfortable in my own skin and I
don’t think this is – I don’t think it’s bad to have autism or anything” (p. 13), he also said he
didn’t know how to bring it up, waited for others to say things that would prompt him to disclose
the diagnosis, and that “I have not told any of my professors except when I get involved with the
disability services there and I may request extended time because I have the papers
[documentation of a disability].” But immediately after acknowledging that “I don’t know when
or how to say it so I was always wait for it to come up” he revealed the uncertainty about
if/when/how his diagnosis should become part of his conversations with instructors by asking the
interviewer “But do you have any thoughts on that yourself? Should I try to be more open with it
or should I have a time and a place to bring it up?”

Although the interviewer redirected the question and this paper’s authors refrain from
offering an opinion on the matter, Edmund had, in practice, consistently answered his own
question, saying “I have not told any of my professors except when I get involved with the
disability services there, and I say, may I request extended time, because I have the papers [from
the disability center confirming his disability]. His pragmatic approach was typical of the
interviewed students, revealing their diagnosis only when they felt it necessary. And even then,
the students were somewhat guarded with their instructors and peers, generally revealing only as
much as was necessary to receive a specific accommodation. When asked whether he talked
about autism with his faculty members, Christopher said,

**Christopher:** That never really came up. That – the extent of my disability was
mainly between myself and the faculty of the disability services center. The only thing that came up between myself and my professors was
hey, I’ve got some issues with taking notes, and test taking. This
document from the SDRC [Student Disabilities Resource Center]
proves that I have a disability and that I need these things. Would you
consent to allowing these things. They were kosher about that. No
harm no foul.
It never really came up with my professors what the nature of my disability was. If they wanted to know they could ask. I didn’t really care either way. Just for the sake of simplicity I just kept mum about the nature. It wasn’t because I was ashamed of it. For the sake of simplicity this is what you need to know that’s it. The less you know the better. Time is precious for you. You don’t need to hear my life story.

For several students, the only people on campus who knew about their diagnosis on the autism spectrum were the staff who coordinate disability accommodations at their institutions. Daniel, in speaking about his forthcoming transition to a major state university, indicated that he “will want a private dorm, which is a disability accommodation. And I’m going to get a long file so it doesn’t seem like I’m just coming up with it suddenly to get a cheap dorm room.” Otherwise, “it just didn’t have any reason to come up” with instructors. Likewise, Franklin never revealed his specific diagnosis when requesting testing accommodations, stating “I just tell them I’m going to take it in a separate room.”

Even more complicated were the interviewees’ considerations regarding disclosure to their student peers. For example, one of Daniel’s in-class experiences forced him to make an on-the-spot decision regarding disclosure to his classmates. During the first session of a sociology class in his fourth semester,

Daniel: We got into small groups and we had to talk about our race, our gender and disability came up so I did mention it quietly and quickly. I don’t think anyone noticed but I did say it... I just felt weird mentioning it.

Later, Daniel expanded on his thinking at the time.

Daniel: They’re people I barely knew because it was the first time any of us had talked to each other. It seemed like an odd time to bring it up but at the same time you know that’s why we were talking was to bring it up so I felt like I had to bring it up but also I didn’t want to so it was quickly and quietly.
Christopher, who was quick to note that his reluctance to disclose details to instructors was strictly pragmatic, seemed somewhat more open to sharing his diagnosis with peers. Some of his classmates knew because “some students, who had noticed that I had to take this form to my professor, they took the initiative to ask. While others, eh, whatever. They didn’t really ask and I didn’t really tell.” Edmund was slightly more forthcoming. When asked if he told people about autism, he responded by stating,

Edmund: I do. I told some of my friends I have it. I don’t tell them right off of the bat. I usually prefer it to come up in conversation or somebody to like question, “Do you have autism?” Some people can even see it and they don’t bring it up. Like I met somebody else over on campus and she said, “I can tell you have Asperger’s syndrome like me because I have it too and I can see it in you. You have like the voice. You have the physical appearance.” I didn’t know there was a physical appearance to it. She said, “You have some of the ticks and things I’ve noticed.” So other people have just said I have autism so eventually when I get to know them well enough.

The only example of full outward acceptance and up-front public disclosure was Brian. When beginning his last class, he reported “I told everybody about my autism and I told them – I said if you have any boundary issues with me, let me know. If I invade your space, let me know…yeah, yeah, I told them everything.” Brian was open and up-front about his condition, and the behavioral manifestations that might be disturbing to others. He saw it as a proactive step to prevent possible misunderstandings with the instructor or other students.

But even is up-front disclosure couldn’t prevent his subsequent dismissal from the class for sexual harassment. Brian’s story may be an extreme example, although Adam mentioned that his autism-related behaviors were most problematic when dealing with potential romantic partners, and there were some indications that Franklin had a major social interaction “incident” that interrupted his college enrollment. But Brian’s detailed explanation of the incident that got
him kicked out of college is illustrative of the manner in which everyday activities can be problematic for students on the autism spectrum.

**Brian:** It was half my fault and half her fault. I talked to the girl – we started out hanging out for lunch. I talked to the girl. We had some projects that we both didn’t have finished. I asked her if you want to go with me to get them done. She said no. I obviously must’ve touched her and made her uncomfortable. She went to the teacher and said ‘this guy is making me uncomfortable.’ He said ‘don’t say anything to her or anything.’ I didn’t. There were other people on the row where she was. When I went up to talk to them obviously when I talked to them I talked to her, I included her in the group because it was a group. She didn’t like that. She complained again. He [the instructor] said ‘you’re still talking to her.’ I said no I’m not. He said ‘just don’t mess with her. Don’t say anything to her.’ I said okay I’m not.

Well her chair was right by the bathroom and when she left she walked right be my chair on her way out every time. It was really bugging me. Finally it bugged me so much that I finally had to say something. When she was leaving one time I said ‘are you still seeing that asshole boyfriend?’ And that was the end of it. A couple days later I got kicked out. The next semester I had to come in – they said I could come back next semester. I wasn’t allowed to come back in that class. I had to come back into a different class.

In Brian’s case, the institution decided that his in-class behavior was so egregious so as to not be excusable because of his disability. Yet, with only one caveat, the school allowed him to return to the institution the next semester. The researchers are not privy to the discussions held by the institutions administrators and, therefore, are not able to assess the manner in which Brian’s autism was a factor in the institutions decision to either dismiss or subsequently re-accept him as a student. But cases like his may indirectly validate the concerns of autistic students who suspect that, in Isabel’s words, “it would be different for me if they knew.”

The concerns about how these students would be treated differently if others knew of their diagnosis appears, in part, to reflect each individual student’s previous experience with disclosure. Adam, who was the only student who asked not to be interviewed on camera,
explained how his experience with a roommate shaped his current hesitancy to disclose his diagnoses of bipolar and Asperger’s syndrome

Adam: I had a roommate that was in the [graduate] program with me that, she was a victim of rape. She was a rape survivor and I, we both knew each other's situations before we started living together and we were both open minded people and thought it would be cool; but it just didn’t work out.

Researcher: You said that you were both open about it so did you tell her?

Adam: Yeah, she said her story first and then I said mine. I said, “All right, you should know that too.” I thought we were kind of, you know – she seemed fine at the time but you know she ended up moving out but when things started to go south, you know, she started using sort of truths about, “You can’t control your behavior and blah, blah, blah”. I don’t want to get into the details of it but just like a lot of what was going – the house was a mess and the, it was the kind of situation – in retrospect I should not have done that. I should not have roomed with her.

Upon initially hearing that story, the interviewer perceived it to be more an example of the practical lessons of interacting with victims of sexual assault than a story central to Adam’s future consideration of disclosure or his development of his personal identity. But when asked whether the topic of autism ever came up during his earlier college experiences, Adam used language suggesting that the episode wounded him deeply and caused him to be more secretive about his disability status:

Adam: It was never used as a weapon against me until now. Everyone else I ever told has been cool with it. I’ve told bosses just as like an insurance policy and just like, “Look, you should know.” I haven’t told my current boss because I work for the state and I just don’t want to. I don’t see any reason to tell them now. It would just, I’m still on probation and so I don’t really want to, I don’t see the reason to do it right now and I’m not having any medical issues at the moment.

To Adam, his disclosure about his diagnoses – which were shared in an effort at openness to and connection with a new roommate – was turned violently against him. And it is telling that immediately after describing the fallout from the roommate incident he describes a dramatic shift
in his disclosure to others who might also be in positions to wound him. The conversation continued by Adam noting that his autism now came up “mostly when I get stressed or sleep deprived, my Asperger’s gets a lot worse.” The conversation continued,

Researcher: What do you mean?
Adam: I’m less able to think about it constantly and suppress it.
Researcher: Is that what you’re doing on a regular basis?
Adam: Every day. I was, that was kind of what I was taught to do, express yourself. You are to pass yourself off as normal as much as you can.

When we cycled back to the topic toward the end of the interview, Adam clarified what he meant about passing himself off as normal.

Researcher: At some point you had mentioned that you had been counseled or taught to not display signs of Asperger’s.
Adam: As a child, yeah. Not... no one ever told me not to do that. I mean no one ever explicitly but in terms of learning what are proper social skills... all of what are proper social skills are things that not Asperger’s. So when I’m told to you know, sit up straight. Don’t fidget. Don’t gesture. Make eye contact. Let the other person talk, finish talking before you talk.

When you’re told all of those things accumulatively over time you get a sense of what normal is or what you’re supposed to be doing and how your, like, base self is not necessarily abnormal but you have to... because society expects certain things, you have to do those things or else you will not go as far in life as you could.

So I’m very proud of the fact that I’m able to fake out as many people as I do, honestly. I mean I know that’s not really a healthy way to relate to one with autism or Asperger’s.

In the process describing his self-governing behavioral modifications, he revealed his struggle to reconcile his “base self” – the autistic self – with the societal pressure to display “normal” behaviors using publicly acceptable social scripts to maximize personal success. His efforts to suppress his autism-related behaviors appears to reinforce the notion that students with autism are rewarded for suppressing their socially-problematic but neurologically natural
behaviors. As he expressed elsewhere in the interview, Adam’s ability to “fake out” people allowed him to “rely on my raw intellect to do what I need to do. And most of the time it worked when I applied myself.” Indeed, it did. At the time of the interview, Adam had completed his bachelor’s degree, two master’s degrees, and was about to complete coursework toward his PhD.

Yet, despite the outward success his approach has brought him, Adam hinted that he had some conscious awareness of the potential problems associated with his approach to navigating his autism-related behaviors.

**Discussion and Recommendations**

Each year, roughly 50,000 individuals in the United States will turn 18 (Autism Speaks, 2012). As interventions supporting young children and K-12 students are increasingly implemented with success, greater numbers than ever before will seek postsecondary education. College educators looking to facilitate the success of these students, however, have few resources from which they can draw empirically-supported, practical tips for working with autistic college students. The current study begins to offer some guidance for those institutions and instructors who wish to take proactive steps to improve the likelihood of postsecondary success for students on the autism spectrum.

This discussion section begins by highlighting some of the challenges facing both students and institutions of higher education as increasing numbers of autistic students seek postsecondary education. The section continues by outlining several recommendations voiced by the autistic students in this study. The paper concludes with a reflective discussion of the apparent conflict between current calls for efficiency within higher education and the inherent inefficiency of working to ensure college success for students on the autism spectrum.

**Ready or Not**
As the rates of early detection rise and the availability of childhood interventions widens, increasing numbers of students with autism will reach the end of their K-12 experiences eager and eligible to move on to institutions of higher education. Regardless of their academic readiness, however, many of these students will come to college conflicted or uncertain about a fundamental component of their identities – the manner in which they have accepted or denied, integrated or ignored their diagnosis with autism.

Other considerable challenges (e.g., living with a roommate, setting one’s own schedule, navigating novel social situations) await autistic individuals entering college, and institutions hoping to facilitate a developmentally appropriate educational experience by balancing challenge and support will thus be required to provide a variety of support services for autistic students. Especially at local open access or community colleges located in students’ hometowns, a common starting point for autistic students (Shadduck et al., 2012), these students may be able to rely on some of the same people, systems, routines, and support services that have helped them succeed in the K-12. Institutions of higher education, however, would be wise not to assume that they can rely on other organizations or individuals to help affected students make a successful transition into and through higher education.

Yet even those institutions wanting to make serious efforts to support autistic college students will face significant barriers themselves. With the number of cases increasing at rapid rates over the last decade, efforts to assist these students will have to scale quickly. Campus-wide strategic initiative committees (or some other institutional committee) will likely not have sufficient time to engage in extensive capital campaigns or even fact-finding missions. Indeed, finding the “facts” about autism on campus is likely to be difficult for several reasons. First, some students who enter college do not know or do not disclose their ASD diagnoses. In the
current study, two of the nine students did not receive a formal ASD diagnosis until after college. Those who do self-disclose often do so only with a narrow range of individuals. When they do disclose, students must provide appropriate documentation to verify their disability status, though some of the students may have been diagnosed as early as 2 or 3 years old and may not have ready access to diagnostic reports. Second, because the symptoms of ASD are holistic – affecting students’ cognitive, interpersonal, and intra-personal domains of development – autistic students may need support services that cross over institutional divisions (academic and student affairs) and units within those divisions (e.g., housing, transportation, registration, testing). However, institutional turf-wars or beliefs that dealing with autism is exclusively the responsibility of a disability service center can interfere with efforts to develop a comprehensive support system. Even laws meant to protect the privacy of students (i.e., FERPA) and patients (i.e., HIPPA) make institutional agents think twice before sharing students’ disability status to colleagues elsewhere within the institution.

Accommodations in Practice

With such entrenched barriers in place, institutions wishing to be proactive may need to move beyond the provision of formal disability accommodations required by law. Nonetheless, although many of the students were reluctant to widely disclose their diagnoses, most had at least contacted the disability services office at their institutions. As a result, those who disclosed were also afforded formal accommodations under the guidelines of the Americans with Disabilities Act. Several students made reference to test-specific accommodations, with extended time and a stimulus-free testing environment most frequently mentioned. The other formal accommodation mentioned by more than one interviewee was on-campus housing without a roommate, essentially getting a “single” room without having to pay extra for it. Somewhat surprisingly,
although three students mentioned housing accommodations – with one student labeling it as a “fairly common accommodation for autistic people” – only one of the students had actually received that accommodation. Moreover, although several students spoke about needing help taking notes in class, only one referenced using a formal accommodations request to acquire such assistance. The students expressed frustration with not being able to keep up and with professors who discouraged or disallowed the use of laptops in class, but they seemed reluctant to seek formal assistance from their institutions. Therefore, institutions may need to take actions that provide more widespread, informal support for these students.

The autistic students interviewed offered a few suggestions that might increase their perceptions of institutional support for students on the autism spectrum. For example, four students made use of tutors to complement their classroom learning activities. Twice referenced as formal support mechanism provide by the institution’s library, tutors were just as often informal and recruited by word of mouth or physical proximity (e.g., person who sat next to the student in class or lived in the same building). All of the students who attended the local community college made reference to free tutoring services made available in the campus library. Not meant to serve only students with disabilities, these tutors were regularly available to help all students struggling with coursework – whatever the subject matter, whatever the students’ difficulty, and regardless of diagnoses. Though not autism-specific, these tutors served as a symbol of the institutions’ commitment to providing extra assistance to students who might need it.

The other common request from the autistic students we interviewed was related to faculty development. Several students suggested that faculty undergo training to recognize some of the signs and symptoms of various mental health challenges, developmental disorders, or
psychiatric conditions. Considering the infrequency with which college faculty are required to engage in formal professional development activities not related to their field of study, this suggestion seems unlikely to be widely adopted. Nonetheless, considering the increasing frequency with which college students are reporting anxiety, depression, and other psychiatric problems (Benton, Robertson, Tseng, Newton, & Benton, 2003; Sax, 1997; Storrie, Ahern, & Tuckett, 2010; Twenge et al., 2010), it may be more critical than ever before that all postsecondary employees know how to recognize and respond to students with mental health complications.

**Conclusion**

Because there is relatively little empirical literature available on ASD student success in college, this study contributes to an essential knowledge base that can inform policies and practices implemented by institutions of higher education. Such an expanded knowledge base is critical, as the development of effective interventions is dependent upon researchers’ comprehensive understanding of the varied and complex set of factors that facilitate or impede the postsecondary success of individuals with ASD.

Although recent efforts to break the silence about Autism (e.g., Autism awareness day/month, “Autism Speaks” website), the voices of individuals with ASD – particularly those who have the interest in and ability to succeed in college – have been drowned out by the overwhelming emphasis (both in the general public and the scholarly literature) on early identification and intervention for young children with autism. By giving voice to a growing population of students who have strong potential for postsecondary success, this study empowers autistic individuals to self-advocate as they consider opportunities for continued educational advancement.
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doi:10.1177/1362361310393363


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The authors acknowledge that there is considerable disagreement about the appropriate use of language associated with autism. For example, although the APA style manual requests “person first” language (e.g., students with an autism spectrum disorder), members of some organizations (e.g., the Autism Self-Advocacy Network) prefer the phrase “autistic student.” Likewise, the students interviewed for this project used a wide variety of terms when describing themselves and others with autism. Moreover, although the APA labels autism as a “disorder” and the medical field speaks of “co-morbid” conditions (other medical or psychological conditions occurring concurrently with autism), some advocates challenge the use of pathological terminology to describe what they view as a manifestation of “neurodiversity.” Complicating matters further is the recent change in the APA’s Diagnostic and Statistical Manual that eliminated Asperger’s Syndrome as a distinct diagnosis and folded it into the broad “Autism Spectrum Disorder” (ASD) label. In this manuscript, we retain the participating students’ language whenever possible, employ both student-first and autism-first conventions, and otherwise use the terms “autism” and “ASD” interchangeably.