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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 by 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 were 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 troths 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 every 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 (Shaddock 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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<sup>i</sup> 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.