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**College experiences for students with Autism Spectrum Disorder (ASD):  
Personal identity, public disclosure, and institutional support**

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**ABSTRACT**

A large and fast-growing population of individuals with Autism Spectrum Disorder (ASD) are completing high school with reasonable expectations for postsecondary success. However, without empirical literature to guide them, college educators are likely ill prepared to provide appropriate support for these students. Drawing from personal interviews with a diverse group of students with autism, the current study (1) amplifies these students' voices, (2) describes tensions between their public and private identities, (3) outlines the academic, social, emotional, self-advocacy, and communication challenges they face in college, and (4) proposes both general principles and specific practices that could be leveraged to facilitate postsecondary success for students with autism.

**College experiences for students with Autism Spectrum Disorder (ASD):  
Personal identity, public disclosure, and institutional support**

A large and fast-growing population of individuals with Autism Spectrum Disorder (ASD)—a neurodevelopmental disorder characterized by impairment in social communication and the presence of restricted interests and/or repetitive behaviors (American Psychiatric Association, 2013)—is completing high school with 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 attempt college within six 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, 2014). Moreover, critical holes in the empirical literature presently make it difficult to develop large-scale, evidence-based interventions for college students with ASD.

The current study begins to fill-in these knowledge gaps by (1) defining salient issues affecting college success for individuals with autism and (2) describing institutional initiatives with potential to promote college success for students with autism. The primary research questions for this study are: (1) How do students with autism make sense of their experiences with higher education, and (2) How do these students respond to potential barriers to postsecondary success? Drawing data from in-person interviews, this study amplifies the voice college students with autism and highlights opportunities to improve their college experiences.

There is considerable disagreement about the appropriate use of language associated with autism (for an overview, see Brown, 2011), with members of some organizations preferring “identity-first” language (e.g., autistic student) while many advocates (and the APA manual) promote “person-first” language (e.g., individual with autism). Recent changes to the formal

diagnostic criteria for autism, conflicting theories regarding its causes, and rapidly increasing rates of diagnosis have undermined any effort to claim the existence of a universal understanding of what is meant by the term “autism.” Indeed, the term has been used differently across time, population, discipline, and measurement mechanism. Therefore, in this manuscript, we use the terms autism, autism spectrum disorder, and ASD interchangeably and follow guidance from the current APA style manual by employing person-first language. However, to maintain authenticity, participant quotes have not been altered, regardless of terminology used.

### **BACKGROUND AND CONTEXT**

To place this study in proper context, we outline four strands of literature. First, we draw heavily from the medical and psychological literature to provide a brief overview of autism spectrum disorders. Next, we describe the growing population of students with autism. We then summarize the major challenges facing college students with autism and highlight several institutional initiatives designed to support these students. Finally, we offer a critical assessment of the available literature by noting the relative infrequency with which that literature has included the actual voices of college students with autism.

#### **Autism Spectrum Disorders**

Recent changes to the formal diagnostic criteria for autism, conflicting theories regarding its causes, and rapidly increasing rates of diagnosis have undermined any effort to claim the existence of a universal understanding of what is meant by the term “autism.” Indeed, the term has been used differently across time, population, discipline, and mechanism of measurement. Although the National Institute of Neurological Disorders and Stroke (2009) propose there is both a genetic and environmental component to autism, clarity regarding its causes remains elusive. By contrast, there exists widespread agreement that autism affects males more than

females (Baio, 2014), and that autism manifests in communication difficulties, challenges with social interactions, and a restricted range of interests (American Psychiatric Association, 1994, 2013; American Psychological Association, 2015; Wing & Gould, 1979).

These characteristics can directly affect students' college experiences. For example, students with autism may be unable to read instructor nonverbal cues and likely struggle with group work (Cai & Richdale, 2015; Freedman, 2010). They may have difficulties with executive functions such as writing to an imagined audience or linking concepts abstractly (Gobbo & Shmulsky, 2014). Those with autism also are prone to anxiety and depression (Liew, Thevaraja, Hong, & Magiati, 2015; van Steensel, Bogels, & Wood, 2013). All of these characteristics can contribute to difficulties in college (Cai & Richdale, 2015; Gobbo & Shmulsky, 2014).

### **Prevalence of Autism in College Students**

Each year, roughly 49,000 individuals diagnosed with autism spectrum disorders (ASD) complete high school (Wei, Wagner, Hudson, Yu, & Javitz, 2015). Approximately 16,000 of those students will subsequently pursue higher education (Wei, Wagner et al., 2015). Rates of autism diagnoses in children have risen dramatically in recent years with rates rising fastest among individuals ages 14–17 and those who have average or better cognitive abilities (Baio, 2014), many who have expectations for access to and success in postsecondary education (Camarena & Sarigiani, 2009; Chiang, Cheung, Hickson, Xiang, & Tsai, 2012). White, Ollendick, and Bray (2011) concluded “between 0.7 percent and 1.9 percent of college students could meet criteria” (p. 683) for ASD.

However, national statistics confirm that only 38.8% of college students with autism will graduate (Newman et al., 2011). This situation is unfortunate, as many individuals with ASD achieve academically at the same or higher levels than their peers without ASD, and would likely

succeed in college with the appropriate supports (VanBergeijk, Klin, & Volkmar, 2008). However, higher education professionals will find little guidance from the current body of empirical literature on individuals with autism within postsecondary education. While the extant literature has tracked basic entry and completion rates for this population, far less is known about these students' experiences while enrolled in institutions of higher education.

### **College Supports for Students with Autism**

A small but growing body of research has focused on intervention programs addressing college students' transitional experiences from secondary to postsecondary education (e.g., Papay & Bambara, 2011; Roberts, 2010). Zager and Alpern's (2010) Campus-Based Inclusion Model (CBIM), for example focuses on the development of social communication skills for transition-aged students with ASD. Under the CBIM, students with ASD enrolled in high school classes on a college campus that "provide(d) a positive, age-appropriate postsecondary option that prepare(d) them for adult living" (Zager & Alpern, 2010, p. 153). While preliminary results of this small pilot study indicated positive outcomes, the study neglects to demonstrate whether participation in a CBIM program contributes to greater success at the postsecondary level, higher college enrollment, or greater job success and satisfaction. A similar study (Papay & Bambara, 2011) examined 87 postsecondary education programs for students with intellectual and other developmental disabilities, but it also neglected to detail the students' experiences within these programs.

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. Barnhill's (2014) survey of 30 institutions of higher education that offer specific support services for students with autism reveals that very few institutions have student outcomes data. Most of the

programs surveyed provided services to students for fewer than five years. These results, however did indicate that institutional efforts to support students with ASD should be both flexible and comprehensive (Barnhill, 2014).

### **Voices of College Students with Autism**

Some scholars have speculated about specific interventions and supports of college students with autism (e.g. VanBergeijk et al., 2008; Roberts, 2010) while others have observed the perspectives of faculty (e.g., Gobbo & Shmulsky, 2014), peers (e.g., Nevill & White, 2011), and parents (Griffin, McMillan, & Hodapp, 2010). However, researchers have collectively failed to validate these observations with the lived experiences of students with ASD. Two exceptions to this critique (Cai & Richdale, 2015; Van Hees, Moyson, & Roeyers, 2014), drawing samples from Europe and Australia, attempt to understand the college experience from the perspective of students with autism. Nonetheless, Gelbar, Smith, and Reichow's (2014) literature review suggests a lack of research on students' experiences and a need for further research 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.

### **CONCEPTUAL FRAMEWORK**

Studies of college students, including those with disabilities (O'Neill, Markward, & French, 2012), are often framed by Astin's (1991) Inputs, Environments, and outcomes (I-E-O) model. The model acknowledges that students' college outcomes (e.g., learning, persistence, graduation) are a function of both the students' backgrounds (e.g., demographics, high school experiences) and their postsecondary environments (e.g., classes, co-curricular activities, use of institutional services). We used Astin's (1991) I-E-O model as a mechanism to organize the topics discussed in our interviews with college students with ASD. 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” 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.

**[Insert Table 1 here]**

## **METHODS**

### **Population and Sample**

The population of interest consists of individuals who have been formally diagnosed with Autism Spectrum Disorder 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,” participants who have not yet attempted college; (2) “Current Students,” participants who are currently enrolled in college; (3) “Departers,” participants who attended a postsecondary institution but left before completing their degree; and (4) “Completers,” participants who completed college and earned a postsecondary credential. Because recent data suggests 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” (2013, p. 234).

The sampling frame for this study included 118 adults with a formal diagnosis of ASD who have registered with the local Center for Autism and Related Disabilities (CARD), a state-funded program providing free support and resources to individuals with autism. The CARD



office, located in a midsize city in the southeastern United States, distributed flyers and emails to eligible individuals and mentioned the study when meeting with clients. However, recruitment of willing participants proved exceptionally difficult. Consistent with the ethical and legal considerations, and as approved by the 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, one of which (Adam; all names are pseudonyms) joined the study 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.

**[Insert Table 2 here]**

### **Setting and Procedures**

Following the guidelines outlined by Fetterman (1998), semi-structured interviews were completed at a location familiar to each of the study participants. At the beginning of each interview participants reviewed an outline of the interview questions that served as tangible guideposts to which the researcher could return when the discussion strayed off topic. 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 fears about going to college, their decisions about whether to disclose their diagnosis of ASD, and their development of academic, social, and independent-living skills. Participants were specifically asked to provide examples of incidents that shaped their college expectations, experiences, and outcomes.

The interviews lasted between 50 and 90 minutes each, with occasional breaks therein as requested by participants. Eight of the nine interviews were video recorded; Adam's interview was recorded with audio only, at his request. 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, also at Adam's request. Each interview was professionally transcribed, with audio/video recordings and transcripts time-synched. Because individuals with autism often experience issues with social communication (APA, 1994, 2013) videos augment written transcripts to allow a more nuanced and comprehensive understanding of participants' responses. The videos were not directly coded during analyses. Rather, they were used to complement analyses of transcripts, with analysts specifically looking for any 1) moments of obvious disconnect between students' verbal responses and non-verbal signals, and 2) outward manifestations of behaviors typically associated with autism (e.g., repetitive body motions).

### **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 interviews with other students. For example, because each of the first two interviewees made specific mention of online or computer-based postsecondary programs, each of the remaining participants were asked specifically about similar experiences. Coding of data from each interview transcript 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 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).

### **Author Positionality**

This paper’s eight authors include undergraduates, graduate students, and faculty researchers from seven fields of study (e.g., higher education, communications, medicine, social work). Moreover, although the American Psychological Association labels autism as a “disorder” and the medical field speaks of “co-morbid” conditions, the authors’ viewpoints generally reflect the more inclusive, interdisciplinary, developmental perspective of advocates who challenge the use of pathological terminology. Among the authors, at least two have immediate family members on the autism spectrum; six of the eight have experiences working directly with individuals with autism. These experiences likely contribute to this paper’s emphasis on hope over fear, on possibilities over problems.

### **Limitations, Credibility, and Transferability**

The study's primary limitation relates to the sample of participants. For example, when compared to national statistics on autism diagnoses (Baio, 2014), participants were disproportionately white, male, and of average or better intellectual ability. The voices of women and underrepresented racial/ethnic students are largely absent from this study. Moreover, because all of the participants were clients of the local Center for Autism and Related Disabilities, they probably had access to supports that might not be available elsewhere. Finally, participants varied in terms of age (both current age and age at time of diagnosis).

Several mechanisms were employed to minimize the limitations and maximize the credibility of the findings reported in this study. First, data triangulation occurred as the lead author not only coded the transcripts from the interviews, but also reviewed notes taken during the interviews, and examined the corresponding videos to ensure interpretation of the quotations was consistent with the students' non-verbal cues. Second, the video recordings also served as a mechanism to check the descriptive accuracy of the transcripts, as researchers were able to view synchronized videos and transcripts simultaneously. Third, investigator triangulation, the use of multiple researchers coding data independently but meeting periodically to ensure convergence, further contributed to descriptive and interpretative validity. Finally, as a form of member-checking and to ensure the voices of participants were accurately reflected in the paper, two of the students interviewed for the study (Adam and Isabel) reviewed and approved a draft of this paper.

Insights gained from this study may be applicable to a wide range of current college students with autism and their postsecondary institutions. Each of the students has had direct interactions with the postsecondary educational system within the last decade, and their

experiences include participation in a wide range of postsecondary institutional types: a for-profit technical school, a community college, an online degree program from a foreign institution, and multiple research-extensive universities in the Southeast United States.

## FINDINGS

Findings from our analyses cluster around two topics. The first (pragmatic disclosure) reflects students' practical approach to a tangible behavioral choice: whether, and when, to disclose their autism diagnosis to others. The second (identity development) describes the subtle tension between students' inward self-acceptance and outward presentation of self.

### **Pragmatic Disclosure**

Students in this study took a pragmatic approach to disclosing their autism diagnosis. Academically, students typically revealed their diagnoses only as needed to acquire formal accommodations from the postsecondary institution. With peers, most interviewees waited until circumstances or another person's actions brought the issue to the surface.

Edmund's approach was typical of the interviewed students. He did not actively attempt to hide his diagnosis, but he was not eager to discuss it either. He said "I don't know when or how to say it so I would always wait for it to come up." Moments later, Edmund further revealed his uncertainty about whether his diagnosis should be part of his conversations with instructors by asking the interviewer "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, 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.

Edmund's tentative but 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, 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,

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 [Disabilities Service Center] proves that I have a disability and that I need these things. Would you consent to allowing these things?’

For several students, the only people on campus who knew about their diagnosis of autism were the staff who coordinated disability-related accommodations at their institutions. Danielle, in speaking about her forthcoming transition from community college to a major state university, indicated she “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, Danielle explained, “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.”

Interviewees also took a pragmatic approach to disclosure with their peers, often only opening up to other students when circumstances required it. For example, one of Danielle’s in-class experiences forced her to make an on-the-spot decision regarding disclosure to her classmates. During the first session of a sociology class in her fourth semester, Danielle said, “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."

Edmund, likewise, allowed circumstances to dictate whether and when he would disclose his diagnosis to peers. When asked if he told people about his diagnosis of autism, he responded by stating, "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?'" Christopher spoke of similar experiences where he told a few of his classmates 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."

Adam, who was the only student who asked not to be interviewed on camera, explained how one negative experience with disclosure shaped his current hesitancy to discuss his diagnoses of bipolar and Asperger's syndrome. When he first told a roommate, "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 tropes about, 'You can't control your behavior and blah, blah, blah.'" To Adam, his disclosure about his diagnoses – which were shared in an effort at openness to and connection with a new roommate – was turned against him. Subsequently, Adam used language suggesting the episode wounded him deeply, saying his diagnosis "was never used as a weapon against me until [the roommate incident]. Everyone else I ever told has been cool with it." But following the incident, Adam describes a dramatic shift in his disclosure to others who might also be in positions to wound him. With a new job, Adam has become more secretive about his status:

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.

### **Identity Development**

Although students took a pragmatic approach to outward disclosure of their autism, their comments also revealed an internal tension regarding the manner in which autism fit into their own sense of identity. The decisions to publicly disclose their status or to seek formal accommodations, therefore, were the outward manifestations of an internal identity development process that was ongoing for each student.

All of the students 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. Gregory described his self-perception while in college using self-deprecating language: "A lot of times I would just think there was something wrong with me or I would probably think I was being lazy. I was goofing off. I wasn't taking something serious. I figured there was something really wrong with me." But in the years since receiving his diagnosis, Gregory has seemed to grow into his own identity, now proudly speaking of his success at national dance exhibitions and public speaking competitions.

The students who received their autism diagnosis early in life expressed a greater comfort with themselves and a generally more positive sense of identity. Edmund, for example, said 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." But even those who seemed more self-accepting hinted at internal tensions related to identity and disability. Danielle, who was reluctant to disclose her ASD diagnosis to others, nonetheless "wrote a paper, my final paper in high school English was on Autism." When presenting the paper, she did not specifically mention she was on the autism spectrum herself,



but claimed “it was obvious, I think” that the paper was somewhat autobiographical. Charlie, when explaining why he didn’t typically tell faculty members about the nature of his diagnosis, added – without prompting and absent any mention of shame elsewhere in the interview – “don’t get me wrong, it wasn’t because I was ashamed of it [autism]”. Charlie’s spontaneous comment seemed to project onto the interviewer the assumption that he should or would be ashamed of his diagnosis, highlighting his awareness that his identity related to autism involved both inward and outward presentations of self.

Navigating the tension between inward acceptance of autism and self-consciousness about external presentations of autism was particularly poignant for Isabel and for Adam. Both of these students were high achievers academically, and both were originally diagnosed early in their lives. Both of them also believed, in Isabel’s words, “it would be different for me if they [other people] knew.” Therefore, both Adam and Isabel generally chose not to share their diagnosis with other people, in part because, as Isabel put it, she had “gotten where I can handle that very well” such that “nobody else really sees what’s happening” when her autism causes her to be “anxious” in “new social situations” or when she is “in a bad mood or stressful situation.”

Adam, likewise, noted that his autism now came up “mostly when I get stressed or sleep deprived... [because] I’m less able to think about it constantly and suppress it.” Asked if he was doing that on a regular basis, Adam responded, “Every day. I was, that was kind of what I was taught to do... You are to pass yourself off as normal as much as you can.” Toward the end of the interview with Adam, the researcher circled back to the topic by asking if he had been counseled or taught to not display signs of autism, to which Adam responded:

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 are 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.

In the process of describing his self-governing behavioral modifications, Adam revealed his struggle to reconcile what he called his "base self" with the societal pressure to display "typical" behaviors using publicly acceptable social scripts to maximize personal success.

His efforts to curb his autism-related behaviors appear to reinforce the notion that students with autism are rewarded for suppressing behaviors that come naturally with autism. Adam had the ability to "fake out" people and that 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." Yet despite the outward success (e.g., full-time employment and two graduate degrees) Adam's statements reveal he had some conscious awareness of the potential problems associated with his approach to navigating his autism-related behaviors when he concluded, "I mean I know that's not really a healthy way to relate to one with autism or Asperger's."

## **DISCUSSION AND RECOMMENDATIONS**

### **Identity, Passing, and the Medical Deficit Model**

For the students interviewed in this study, there exists a recognizable tension between their public efforts to "pass" themselves off as "typical" and their private efforts to embrace autism as part of their unique identities. Such a tension will be familiar to those in the field of

disability studies (see Brune & Wilson, 2013). Moreover, the manner in which students navigate similar tensions undergirds several theories related to race, ethnicity, sexuality, and sexual identity development (e.g., Cross & Fhagen-Smith, 2001; D'Augelli, Hershberger, & Pilkington, 1998; Fassinger & Miller, 1997). The parallel to theories of sexual identity development (D'Augelli, Hershberger, & Pilkington, 1998; Fassinger & Miller, 1997) is particularly clear, as both autism and sexuality are pieces of identity that can remain somewhat hidden to the outside world. Students with these identities may decide to actively conceal their status and present themselves as “a member of the dominant privileged group” (Valeras, 2010). Like Cox (2013), many of the students interviewed for this study had developed specific social scripts or rules to follow to avoid outing themselves as an individual with autism. These students’ consideration of whether and when to “come out” involves consideration not only of who they are, but also how they would be perceived by the culture in which they operate.

Indeed, there is some evidence to suggest that students’ own sense of identity has been shaped by others’ perceptions. The students in this study regularly used language (e.g., “cross-wired” or “something wrong with me” or “abnormal”) reflective of society’s common use of the deficit-based medical model of autism. In this model, individuals with autism are considered flawed (genetically) or deficient (cognitively, socially, or behaviorally). It may also be reflective of a long-held assumption that disability is a binary construct in which an individual is either “normal” or “disabled” – an assumption that has been challenged by current disability studies scholars (e.g., Brune & Wilson, 2013). Such a simplistic, deficit-based model is easy to adopt, even if unconsciously, as this paper’s authors did in earlier versions of this manuscript..

There is, however, a growing socio-political movement challenging society to move away from the deficit model of disabilities (Carey, 2013). Autism self-advocacy groups like the

Autistic Self-Advocacy Network (ASAN) have long embraced the idea of neurodiversity, challenged the medical model, and questioned the use of person-first language (Brown, 2011). Even within the fields of psychology and medicine, where the deficit model is most pervasive, some leading scholars (e.g., Stewart, Allison, Baron-Cohen, & Watson, 2015) have moved away from labeling autism as a “disorder.” Instead, these scholars refer to autism as a “condition” and often emphasize the presence of autism-related traits within the general population.

Within higher education, educators can promote an environment in which individuals with autism can safely explore their own identity development and feel comfortable disclosing their diagnosis to higher education professionals without receiving the assumed societal stigma. To create such an environment, Hadley (2011) encourages administrators to consider disability within a framework of student development. Taylor (2011) urges higher education to embrace disability status as a component of diversity. Regardless of the manner in which one frames autism, over the coming decades, college educators increasingly will be charged with supporting the postsecondary success of this growing student population.

### **Ready or Not**

As the rates of early detection of autism rise and the availability of childhood interventions widens, increasing numbers of students with autism will reach the end of their K-12 educational experiences eager and eligible to move on to institutions of higher education. Regardless of their academic readiness, 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 transition experiences (e.g., living with a roommate, setting one’s own schedule, navigating novel social situations) await individuals with ASD entering college. Institutions

hoping to facilitate a developmentally appropriate educational experience will thus be required to provide a variety of support services for students with autism. Especially at open access or community colleges, common starting points for students with ASD (Shattuck et al., 2012), 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 system. Institutions of higher education, however, would be wise not to assume students with autism can rely on outside organizations or individuals to help students make a successful transition into and through higher education. Effective and appropriate institutional supports are needed.

However, institutions wanting to make serious efforts to help support college students with ASD face significant barriers. With the number of diagnoses of autism increasing, 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, many students who enter college do not know of their diagnosis (Langford-Von Glahn, Zakrajsek, & Pletcher-Rood, 2008; VanBergeijk et al, 2008), do not consider themselves to have a disability (Newman et al., 2011), or do not choose to disclose their diagnosis (Cai & Richdale, 2015; Van Hees, Moyson, & Roeyers, 2014; Fleischer, 2012; White et al., 2011). In the current study, two of the nine students did not receive a formal ASD diagnosis until after college. Students who self-disclose often do so only with a narrow range of individuals, and only when they deem it necessary. At many institutions, and counter to the guidance from the Association on Higher Education and Disability (Lovett & Nelson, 2015), students requesting accommodations must provide documentation to verify their disability status. Yet, some of the students may have been diagnosed as early as 2 or 3 years of

age and may not have ready access to diagnostic reports.

Second, because the symptoms of autism are holistic – affecting students’ cognitive, interpersonal, and intra-personal domains of development – students with ASD may need support services that cross over institutional divisions and units within those divisions (e.g., housing, transportation, registration, testing). However, beliefs that supporting students with autism is primarily 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) can make institutional agents think twice before sharing students’ disability status with colleagues elsewhere within the institution.

### **Institutional Responses**

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 or provided by a specialized disability services office. It may be more critical than ever before that all postsecondary employees know how to recognize and respond to students with a variety of disabilities. For, despite the increasing frequency with which college students are reporting anxiety, depression, and other psychiatric conditions (Benton, Robertson, Tseng, Newton, & Benton, 2003; Sax, 1997; Storrie, Ahern, & Tuckett, 2010; Twenge et al., 2010) – conditions that often accompany autism – campus counseling centers are being stretched financially (Gallagher, 2012; Mistler et al., 2012) and may not be able to meet the increasing need for psychological support among college students. Some scholars (e.g., Bishop, 2006, 2010; Bundy & Benshoff, 2000; Kadison & DiGeronimo, 2004) have noted that, in this national environment of increasing need but decreasing resources for counselling centers, institutions could even leverage well-appointed counselling centers as a competitive advantage during student recruitment.

More broadly, institutions can develop campus climates of inclusion in which students feel safe to both teach and to learn about student differences. Campus climate has been highlighted as critical to the experiences of many student populations (e.g., Johnson, Wasserman, Yildirim, & Yanai, 2013; Rankin, 2005; Rockenbach, Mayhew, & Bowman, 2015). Changing those climates, which often reflect long-held and deeply entrenched cultural norms, remains a challenge at many institutions. Edgar Schein (2004) has identified several mechanisms through which leaders use institutional policies, programs, and practices (e.g., crisis response, resource allocation, formal statements) to shape, transmit, and potentially change culture. Dean Spade's (2015) alternative approach, rooted in the Four Pillars of Social Justice Infrastructure developed by the Miami Workers Center, argues transformative change requires more comprehensive efforts. Policy-related efforts should be interwoven with efforts to raise consciousness of, provide service to, and distribute power throughout a marginalized population.

Creative administrators looking to change institutional cultures and improve campus climates for individuals with autism may find the concept of Universal Design (UD) a welcome bridge between Schein's (2004) traditional organizational approach and Spade's (2015) more activist approach. Universal design might also be palatable to institutional leaders who are under increasing public and governmental pressure to distribute resources in an efficient manner while simultaneously being responsive to the changing and diverse student populations within their institutions. Although it may be impossible to create an environment supportive of all populations in all situations, universal design can guide a process in which usability is constantly assessed, evaluated, and revised to ensure the greatest utility for the greatest number of users.

Universal design is rooted in seven principles applicable in any environment: (1) equitable use; (2) flexibility in use; (3) simple and intuitive use; (4) perceptible information; (5)

tolerance for error; (6) low physical effort, and (7) size and space for approach and use (The Center for Universal Design, 1997; Burgstahler & Cory, 2008). Application of these principles can have wide-ranging effects, providing support to students with autism while simultaneously meeting the needs of an increasingly diverse college population. With invisible disabilities like ASD, faculty and staff might not recognize immediate needs for targeted supports. Whether the need for support is obvious or hidden, “anxiety, confusion, and the prospect of failure for these students may be reduced through the implementation of basic principles of universal design” (Spencer & Romero, 2008, p. 145). As Burgstahler and Cory (2008) state, although “you can never finish implementing UDHE [universal design in higher education], it is easy to get started and then to continue taking incremental steps” (p. 3).

For example, campus housing can provide a supportive living community for all students, but the added support of peer mentors and the convenience of on-campus facilities may be particularly valuable to students with autism. A student with ASD may need accommodations to navigate the communal nature of residence halls, which typically include roommates and social programming. Institutions should offer a single housing option to students with ASD. A single room option as part of a larger community recognizes student independence while providing a transitional space to engage in communal activity. Resident Assistants (RA) should also have a basic understanding of the needs and special considerations of this population, as the RA can serve as a mentor and prevalent figure for students living on campus. Therefore, RA training should include a session on understanding various student populations, including students with ASD, in order to create the safest and most inclusive space possible within the residence halls. Furthermore, housing professionals should refocus social programming to include life skills, such as doing laundry, cooking on campus, and managing personal finances. These programs



would benefit all students, but would have particular appeal and value for students with ASD.

### CONCLUSION

For most of the interviewed students, going to college represented a major life event described in ways similar to what one would expect to hear from any college student. But going back to college was particularly important for Brian, a 50+ year-old man who attempted suicide on several occasions over the preceding two decades and who had been kicked out of a technical college course within the year preceding his interview. When reflecting on his forthcoming re-enrollment in a computer design course at that same institution, 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.” His story highlights the potential importance of postsecondary education to this population, where even a single course can give students hope for the future.

This study contributes to an essential knowledge base that can inform policies and practices that may give other students with autism similar hope. 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 and challenge postsecondary success of individuals with ASD. By amplifying the voice of a growing population of college students who have strong potential for postsecondary success, this study empowers individuals with autism to self-advocate as they consider opportunities for continued educational advancement. However, it is up to the professionals who work in postsecondary education to listen to these voices and shape a college environment that helps students with autism transform personal optimism into systematic success.

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Table 1

Five-Part Semi-Structured Interview Protocol (Fetterman, 1998) using Astin's (1991) I-E-O Model

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1. Confirmation of Consent & Reminder of Study Purpose
    - a. *"OK, I've just turned on the camera and we're about to begin the interview. I want to be sure everything has been clear thus far, so, can you give me a quick summary of what we'll be doing for the next hour or so?"* Main topics:
      - i. Personal, family, and educational background,
      - ii. Preparations for, expectations of, and experiences related to college, and
      - iii. Outcomes associated with decisions and experiences in postsecondary education.
    - b. *"Do you have any questions at this time? Feel free to stop me any time if questions come up later."*
  2. Inputs - Background
    - a. *"OK, then let's get started... Please tell me a little bit about your life growing up?"*
      - i. People: Family, Friends, Teachers, etc.
      - ii. Places: Home, School, Therapy, Work, etc.
      - iii. YOU: Favorite things to do, best subjects in school, interests, hobbies
    - b. *"When you were growing up, what were your plans/ideas for life after high school?"*
      - i. Where to live (with family, friends, by self)
      - ii. What to do (work, college, homemaker)
      - iii. Resources/People – What influenced your thinking about life after HS?
      - iv. What really happened: Did everything go as you expected? Why/not?
  3. Environments - College Experiences
    - a. *"Let's talk about your college experiences... what's college been like for you?"*
      - i. Overarching Path: College/Program type, timeline
      - ii. Academic: Major, courses, studying, tests, grades
      - iii. Social: Classmates, roommates, making friends, meals, clubs, parties
      - iv. Everyday life: Getting around, life-management, *day in the life...*
    - b. *"How did you ASD come into play in college? Did you tell people? Ask for accommodations?"*
      - i. Disclosure of ASD: Admissions, SDRC, instructors, peers
      - ii. Support Service Use: Disability Services, Counselors, Advisors
  4. Outcomes - Postsecondary Plans and/or Outcomes
    - a. *"Tell me about the current status and future plans for higher education?"*
      - i. Current Status: Grades, # of courses
      - ii. Plans: Short term (summer & fall) & Long-Term (after current program) (Graduation, transfer, internships, grad-school, career)
    - b. *"What do you get out of college? How have you benefitted from your college experiences?"*
      - i. Benefits? Academic, social, psychological, occupational, life skills
      - ii. Costs? Financial, personal, family/friends
  5. Summary & Wrap up
    - a. *"OK, last part. We've talked about a lot of things today, so I'd like to take the last few minutes to ask a few overarching/summary questions... are you OK to continue for a few more minutes?"*
    - b. *"What has been most helpful as you've strived for college success?"*
    - c. *"What have been the biggest impediments to your college success?"*
    - d. *"Do you have any specific ideas about how to facilitate college success for students on the autism spectrum?"*
    - e. *"Anything else, perhaps something we didn't discuss already, that you want to be sure I know about this topic?"*
- Note. Italicized items are primary questions read aloud nearly verbatim; small roman numerals indicate potential probes/follow-ups.

Table 2  
 Characteristics of Interview Participants

Participant	Age	Sex	Gender	Age of ASD Diagnosis	Highest Degree Completed	Active/Pending Enrollment
Adam	30+	Male	Male	3	Master's Degree	Doctoral Program
Brian	50+	Male	Male	In his 40s	High School	Technical School
Christopher	24	Male	Male	8 or 9	Bachelor's Degree	
Danielle <sup>1</sup>	20+	Male	Female	9	High School	Community College
Edmund	21	Male	Male	15 or 16	GED	Community College
Franklin	23	Male	Male		High School	Community College
Gregg	33	Male	Male	26	Bachelor's Degree	
Harper	19	Male	Male		GED	
Isabel	18	Female	Female	4 or 5		High School Senior

<sup>1</sup> Danielle, (born male), spoke of experiencing gender dysphoria and was seeking hormone treatments.