

A Spectrum of Student Success: Identifying Factors Affecting Access, Experiences, and Outcomes for Students on the Autism Spectrum

Purpose

One of every 68 children in the United States has autism (Autism Spectrum Disorder, or ASD for short) (Christenson, Baio, Braun, et al., 2016) a rate of diagnosis that has more than doubled during the last 10 years (Baio, 2014; Christenson, Baio, Braun, et al., 2016). With recent increases in public awareness, early interventions, and K-12 educational support, an increasing number of these students ready and able to pursue higher education (Camarena & Sarigiani, 2009; Chiang, Cheung, Hickson, Xiang, & Tsai, 2012). But statistics about college access and outcomes for this population are disheartening, especially considering that many individuals with ASD achieve academically at the same or higher levels than their typical peers, and would likely succeed at the college level with appropriate support (VanBergeijk, Klin, & Volkmar, 2008). Data from a national sample of teenagers with autism indicate that only 34.7% of these students attend a 2- or 4-year college (Shattuck et al., 2012), and fewer than 39% of those who enter earn any form of credential within 6 years (Newman et al., 2011).

As more and more students with autism show up on college campuses, it has become increasingly important for college educators to understand these students' experiences and actively address the underlying challenges that have heretofore contributed to the relatively poor college outcomes for this population. Although a small, but growing, number of studies have begun to explore the experiences and outcomes of college students with autism, the current body of literature is limited in three significant ways. First, a disproportionate number of these studies draw from a narrowly constructed, single dataset (the NLTS-2) that has not been updated since 2009. Second, the vast majority of studies not using NLTS-2 are based on data collected from people other than the students with autism themselves (e.g., parents, instructors, college disability service office administrators). Third, although these studies have generated myriad statistical comparisons, they have yet to yield a comprehensive conceptual model that could be used to help students or their institutions anticipate, address, and overcome challenges that heretofore might undermine the chances of college success for autistic students.

The current study addresses all three of these limitations by building a conceptual model based on evidence generated through direct interviews with a diverse group of individuals with autism who had experiences with a wide range of postsecondary educational institutions.

Background and Context

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder characterized by “persistent deficits in social communication and social interaction across multiple contexts” and “restricted, repetitive patterns of behavior, interests, or activities” (APA 2013). The population of individuals with ASD who have completed high school is rapidly increasing, with 34.7% of students with ASD attending college during the first six years after graduating high school (Shattuck et. al., 2012). Using the most conservative available estimate, at least 16,000 students with autism enter college each year (Wei, Wagner, Hudson, Yu, & Javitz, 2015). These statistics, however, are drawn from a decade-old database that generally does not include sub-clinical populations, those who don't receive a diagnosis until after they graduate high school, or those who choose not to use their disability status to seek accommodations in K-12 schools. Extrapolation from a single-institution study from White, Ollendick, and Bray (2011) to the entire population of college students in the United States (Hussar & Bailey, 2016) suggests that

between 143,500 and 389,500 students with autism are currently in college.

Put simply, we do not know precisely how many college students have autism, but their numbers are nontrivial and are expanding at an exponential rate. Moreover, because many other students have some characteristics of autism (e.g., maladaptive repetitive behaviors, rigidity in routine or habits of thought) even if they don't meet a formal clinical diagnostic standard, autism really affects the entire student body - especially when we consider that neurotypical students (those without autism or related developmental conditions) are likely to encounter at least one autistic student in their residence hall, dining facility, or classroom.

The literature on college students with autism, and the institutional initiatives designed to support them, is remarkably thin. A review by Pena (2014) revealed that the field's top 4 journals had published, collectively from 1990-2010, barely one article per year focused on students with any disability; to date, there has not been a single published article in these four journals to use the word autism. The available literature from other sources indicates that students with autism may struggle with social interactions or engage in classroom behaviors that can undermine their chances of success (Cai & Richdale, 2015; Gobbo & Shmulsky, 2014; Lainhart, 1999). Collectively, this body of literature suggests that White et al. (2011) were correct when they warned that the forthcoming influx of college students with autism would create "a considerable challenge for which [colleges and universities] may be ill-prepared" (p. 697).

Method

The current study takes a grounded theory (Corbin & Strauss, 2008; Charmaz, 2006) approach to gain a better understanding of this population, student experiences in college, and the mechanisms through which institutions of postsecondary education could facilitate these students' success. Drawing data from a series of in-depth interviews with students on the autism spectrum, we employed an *a priori* initial coding structure based on Astin's (1991) Inputs - Environments - Outputs (IEO) model, developed a set of tentative propositions, and went through multiple iterations of subsequent data analysis. We continually generated, supported, challenged, and refined a series of propositions grounded in and checked against the raw data from the interview transcripts and videos. Efforts to integrate the resulting propositions ultimately led to a comprehensive conceptual model that can be used to guide postsecondary educational policy, practice, and research.

The analyses of these data occurred in three distinct phases. During Phase 1, throughout the data collection process, we took a constant comparative approach (Straus & Corbin, 1998) whereby data collection and analyses were conducted iteratively, with concepts from previous interviews explicitly explored in interviews with other students. Phase 2 of the analyses involved coding the interview transcripts using the I-E-O framework as an a-priori descriptive coding structure. These coders had previously used the same coding structure to analyze 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 coders also wrote reflective memos and created new codes as they recognized patterns of interview segments that did not fit into the a-priori coding structure.

Phase 3 of analyses involved a 12-step process (Steps 3a-3i) that combined elements of grounded theory, multiple case-study, and constant comparative approaches to analyses. In steps 3a-3f, two of this paper's authors used the data generated during the first two phases of the study to develop, refine, and support a series of "propositions," roughly analogous to the causal chains typical of grounded theory that were 1) testable, 2) relational, 3) insightful, and 4) actionable. In

step 3g, the authors who generated the propositions traded propositions and went in search of *disconfirming* or *contradictory* evidence from the first two phases of the study. In Step 3h, all four authors met to compare the confirming and disconfirming evidence to determine whether the weight of the evidence supported the proposition as written, suggested the need for further refinement of the proposition, or invalidated the proposition altogether. Finally, in Phase 3i, the first three authors met again to discuss the revised propositions in an attempt to reach consensus regarding the final language for the propositions. This extensive, iterative, and interactive analytical process ensures descriptive accuracy, provides multiple forms of triangulation, and helps protect against potential threats to credibility.

Findings or Results

The iterative process of assessing and revising a series of propositions yielded increasingly refined propositions grounded in the interview data. However, during what we thought was going to be our final reconciliation meeting, where we would ensure consensus regarding the final wording of these propositions, we struggled to finalize the language in such way that would ensure each proposition was distinctive from the others while simultaneously remaining true to the data from which they were derived. Recognizing that our students' experiences were complex and occasionally messy, we realized that each of the ideas expressed in our propositions occurred in relation to other components of our propositions. Subsequently, we sought to reconcile the propositions visually, deconstructing them as distinct propositions and reconstructing them as a series of connected concepts. The resulting model is best presented visually (see Figure 1) as a series of intersecting points between the individual with autism and the institution the student attends.

Student Step 1: Autism Related Characteristics

Presentation of the model begins in the bottom left-hand corner of Figure 1, which highlights the manifestations of autism that the students bring with them to college. One of the most common autism-related characteristics are difficulties with social communication and peer interaction. Without a natural inclination to recognize or use "proper social skills," Gregory, for example, was reluctant to approach peers for fear of saying something "silly" or "stupid." Edmund lamented that "everybody else had been learning [social skills] naturally and with ease. But it had been very difficult [for me], I have never been able to grasp. And the thing is they don't teach you that kind of stuff in school."

Institution Step 1: Standard Operating Procedures

Students in our study identified several Institutional norms, policies, and practices - what we collectively label standard operating procedures - that neither appeared to consider nor proactively accommodated the distinctive characteristics of students with autism. Thus, what many institutions considered straightforward day-to-day activities could be particularly difficult for students with autism.

Convergence Step 1: Problem Realization

Students in our study recognized several points of incongruence between the personal characteristics they associated with autism and their institutions' standard operating procedures. In some respects, the participants in our study encountered challenges similar to those many other students experience when entering higher education. Like many new college students, Edmund "had difficulty keeping, you know, interest at some points," while Adam acknowledged "I procrastinated. I wasted time. I goofed off." Similarly, Franklin struggled in a science class that was "going very fast and I can't handle it." Other students, including Edmund, struggled to

cope with a full load of college courses. Edmund eventually realized that enrolling in four courses was “too much to handle.” He continued, “I had a lot of restless nights. I had a lot of tired days. I had a lot of days I was so tired I didn’t eat anything all day and I just went to sleep... I was zombified.”

<<step 2 not included in abstract to save space>>

Student Step 3: Personal Connections

After redefining a problem, some students were able to identify, develop, or reconnect with a personal support network or individual institutional agent whose personalized interactions supported the student’s pursuit of holistic well-being. As Christopher noted, “You’ve gotta be around the right people. If your family and friends aren’t supportive of you and your goals aren’t willing to acknowledge that you’ve got this thing and aren’t willing to help you overcome it, the chances are already stacked against you. Maybe you can overcome it with just you by yourself but, like I said, the odds are slim. You really need to have a support structure of some kind to help you.”

Institution Step 3: Personalized Adaptation

Students who were able to make strong connections with institutional representatives were often recipients of what we have termed *personalized adaptation*, defined as instances in which institutional resources, norms, accommodations, or policies were seen as malleable and adaptable to the needs of the individual student with autism. These instances were not typical of the institution nor indicative of a larger program or initiative to support students with autism; rather, they came when the student with autism happened upon an individual (instructor, staff member, or administrator) who took a special interest in the student.

Convergence Step 3: (Re)Solving the Problem

By leveraging their connections to a personal support system, and by embracing the personalized adaptations some students received from their postsecondary institutions, some students were able to solve problems that – though initially recognized when the students’ autism-related characteristics intersected with colleges’ standard operating procedures – had been subsequently redefined as individuals’ sense of identity shaped their responses to institutions’ formal accommodation efforts. Piecemeal solutions to unique problems, however, do not appear to be permanent or easily transferable to other contexts. Students spoke of navigating similar problems in multiple settings over extended periods of time. And institutions may not easily translate personalized adaptations into institution-wide policy, practice, or culture. Therefore, Adam suggested institutions could implement “some way of structuring the college experience so that people like, especially, you know, Autistic people or Asperger’s people who need more support or could use more support to somehow remind them in a formal way that these services exist without you know making a big fuss about it.”

Discussion & Implications

Students with autism have flown under the radar at colleges and universities across the United States. The population has thus far gone unmentioned our field’s top research journals, is overlooked on many campuses because autism is generally an invisible disability, and may be ignored by faculty members or administrators who believe these students’ needs are being met by the accommodations provided through an institution’s disability service center. Although notable exceptions exist, current policies, practices, structures, and cultures in US institutions of higher education do not appear well suited to facilitate college success for students on the autism spectrum. The model presented in this paper provides a descriptive portrait of how the

interviewed students experienced interactions with their postsecondary institutions. The model can also be used to guide proactive efforts on the part of both students and institutions who are committed to college success for students on the autism spectrum.

Getting Ahead of Predictable Problems

Our model suggests that college students with autism initially encounter problems when the students' autism related characteristics intersect with institutions' standard operating procedures. Findings from our study, and other research examining the postsecondary experience of students on the autism spectrum, provide initial evidence with which educators could anticipate likely points of intersection between institutions standard operating procedures and the characteristics of individuals with autism. Simply put, we can anticipate where students with autism are likely to run into problems with the way institutions normally operate. If we can anticipate where these points of tension may occur, institutions may be able to proactively take steps to "get ahead of the problem."

Moving Beyond the Disability Service Center

Nearly all the students interviewed for the study made specific mention of a disability service center on campus. For these students, the disability service center was the natural starting place when considering how the institution responds to their needs. Though many centers such as this offer generic services for students (extended time on tests, note taking services) and have expert for a variety of learning disabilities or impairments, having a specific advisor (or "case worker" of sorts) for students with autism would be an enormous benefit in helping them navigate institutional frameworks. This case worker could serve as a consistent point of contact for neurodiverse students at the institution. As many large university departments work in a siloed fashion, trying to accommodate students across functional areas can lead to concerns of FERPA violations, especially if the administrator is not familiar with the needs of ASD students. Even without the resources to implement specialized positions, institutions can still make subtle changes to support students with autism. Updating websites to make procedural information more easily accessible can provide students with autism with a starting point for resolving problems. Liberal advertising of co-curricular resources (e.g. tutoring center, counseling center) can be implemented or directly sent to students who have indicated that they may need some additional assistance. Student affairs professionals could join academic instructors to provide workshops regarding campus involvement and/or socialization into the academic community, which a number of students in this study said would be necessary to succeed in college.

Conclusion

Ten years ago, 1 in 150 8-year-old children was diagnosed with an autism spectrum disorder. Today, the number is 1 in 68. Ten years from now, when this year's 8-year-olds turn 18 and look to make the transition to college, their ranks will include more students with autism than ever before. As the number of students with autism going college has risen, it has become increasingly necessary for institutions of postsecondary education to recognize and respond to the growing number of students with autism on their campuses. But campuses can do more than just respond to specific incident when a specific student asks for specific accommodations under a specific legal authority. Using the model presented in this paper, colleges and universities can take proactive steps to facilitate the success of college students with autism.

Appendix A – References

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Appendix B - Tables and Figures

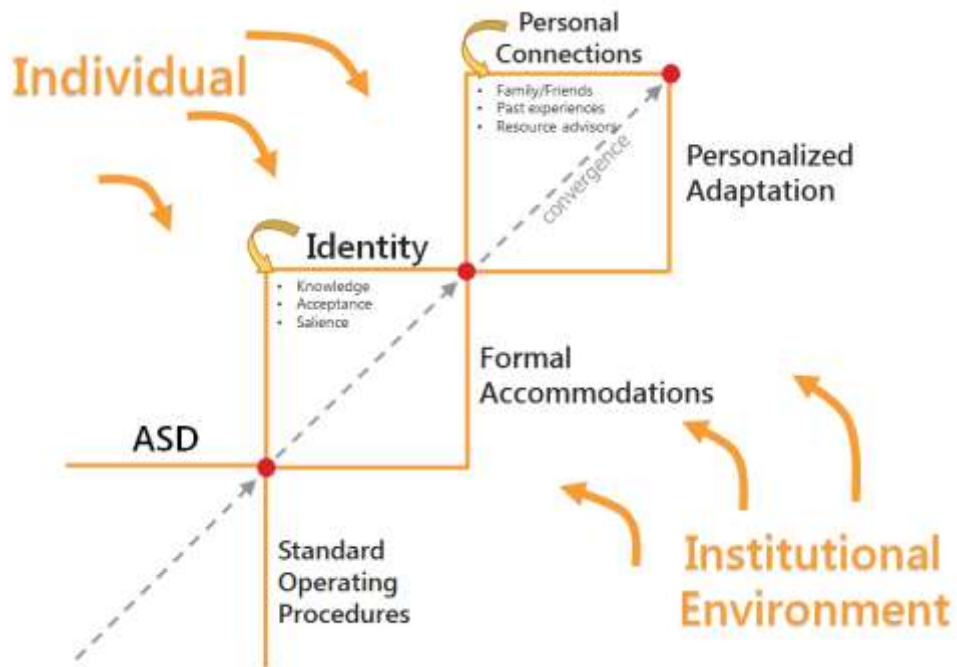


Figure 1: Model of convergence between postsecondary institutions and students with autism