Beyond Access: Exploring Support & Services for Students with ASD that Lead to Success

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Twenty years ago, it was estimated that 1 in 150 children would be diagnosed with autism spectrum disorder (ASD). In 2021, that estimation has risen to 1 in 59 (Cox, Edelstein, Brogdon & Roy, 2021). Viezel, Williams, & Dotson (2020) estimate that in 2020, over 430,000 students (1.9%) enrolled in US higher education institutions will meet the diagnostic criteria for this condition. Students with ASD (SwASD) are eligible for reasonable accommodations and support at their institution through the Americans with Disabilities Act and section 504 of the Rehabilitation Act of 1973 (Viezel et al., 2020). These laws, along with a growing body of research that supports the implementation of successful early intervention techniques alongside school-based services, may facilitate an increase of promising students with ASD entering higher education in the future - especially as an estimated 50,000 youth with ASD turn 18 each year (Shattuck et al., 2014). Despite the gains in enrollment and the availability of legally mandated accessibility services post-enrollment, fewer than 40% of SwASD who start college will earn a postsecondary degree compared to 60% of their neurotypical peers (Accardo, Kuder, & Woodruff, 2019). The achievement gap for SwASD indicates a need for higher education institutions to explore how this population can engage with their school beyond access and identify which services will lead to student success. This review of literature will identify the challenges and needs of SwASD, explore potential methods for supporting the success of this student group, and offer suggestions for future research that will benefit institutions, practitioners, and college-going individuals with ASD and their families.

Student affairs professionals must have a working knowledge of the characteristics of autism spectrum disorder to begin understanding the needs of this student population. In addition, it is important to note that medical definitions and diagnoses are dynamic and thus subject to change over time or by individual. Per the Diagnostic and Statistical Manual of Mental Disorders Text Revision Fourth Edition, ASD is a lifelong neurodevelopmental condition, typically characterized by “difficulties in social interaction and communication, in addition to repetitive behaviors and restricted interests [which may also be accompanied] by a high degree of rigidity” in day-to-day life (White, Ollendick & Bray, 2016, p. 684). It is important, however, for practitioners to remember that the symptomology and severity of ASD is heterogeneous, meaning that individuals each uniquely experience these traits along a ‘spectrum’ of severity

(Gobbo & Shmulsky, 2014, Obeid, Bisson & Cosenza et al., 2021). From these general guidelines, an institution can expect that SwASD will need support with “social communication, handling the lack of structure and routine in college, executive functioning requirements, managing time and unexpected change, and managing comorbid conditions” to varying degrees (Accardo & Kuder et. al, 2019, p. 574). These needs may create challenges for college students with ASD, including accessing and receiving appropriate support services, navigating academic campus spaces, and adjusting to the new social environments presented in the collegiate experience.

Challenges for Students with ASD

While appropriate accommodations for SwASD can be accessed via an institution’s federally mandated disability services office, Viezel et al. (2020) found that only 36.7% of SwASD “felt they were getting the appropriate amount of support” through their college-based accommodations, while an additional 54.1% of SwASD did not receive any college-based accommodations (p. 236). One potential contributor to these low percentages may be tied to internalized social stigmas held by SwASD. White et al. (2019) notes that misconceptions about autism often contribute to the stigmatization and exclusion of this population, driving them to ignore or downplay their diagnosis. A 2002 National Center for Education Statistics report found that while 9% of students nationwide enrolled in disability services, only 4% regarded themselves as having a disability (Horn et al., 2002). Similarly, when Shattuck et al. (2014) studied a group of 120 SwASD, they discovered that around a third of participants reported not perceiving themselves as “disabled or having a special need” at all (p. 1). Another possible reason for this low rate of participation is difficulty in obtaining an autism diagnosis. White et al.’s (2016) survey-based study of the prevalence of autism at a large, public southeastern university in the United States uncovered five students who met diagnostic criteria but were unaware they qualified for a diagnosis. Considering that their institution’s disability office reported a total of just 10 enrolled SwASD at the time, this 50% increase in known students with autism via a single study may be an indicator that a significant number of students nationwide are also undiagnosed. Additionally, significant delays in diagnosis for “racial and ethnic minority groups, economically disadvantaged children, and girls” have been consistently documented in autism research, potentially compounding the challenges that many low-income, female and people of color already face when trying to access higher education (Obeid et al., 2021, p. 106, Mandy & Lai, 2017).

Even after students have obtained a diagnosis, they often face challenges registering at their school’s disability office. Some students reported needing recent diagnosis and extensive

documentation in order to receive accommodations, a challenge for both students with a history of accommodations but no recent diagnostic paperwork and those with recent diagnosis but no history of accommodations (Cox, Edelstein, Brogdon & Roy, 2021). Armstrong & Hamilton (2018) observed that at-risk students struggling at college are often "ill-equipped" to seek out support or unaware that they need help (p. 17). With the onus for requesting these services placed on individual students, navigating this challenging bureaucracy with the typically limited social and/or communication skills that accompany ASD can be a major hurdle. The combination of stressful new social situations and lack of information about how to access support services doubly burdens SwASD. The stress of navigating these extensive bureaucratic processes drive some students to 'mask' their neurodivergent characteristics or delay the disclosure of their diagnosis until their challenges have become too overwhelming to handle alone (Viezel et al., 2020, Nachman, Miller & Vallejo Peña, 2020, Accardo & Bean et al., 2019).

Another prevalent challenge for SwASD is engaging in academic spaces, including classrooms, group work, and faculty interactions. As difficulties with social communication are common with this student group, student performance can be affected by difficulties in "understanding classroom norms, rules, and expectations" as well as struggling with recognizing appropriate tone and topics in the class, frequency of speech during discussions, and interpreting the perspectives of their peers while working in groups (Viezel et al., 2020, p. 235, Gobbo & Shmulsky, 2014). Interacting with faculty one-on-one can pose additional challenges. SwASD reported that faculty members regularly pushed them to other school entities (i.e., advisors or disability offices) and often appeared uncomfortable with discussing ASD-related topics (Cox et al., 2021). There may be several reasons for this discomfort, including valid concerns about violating well-known federal laws such as the Family Educational Rights and Privacy Act (FERPA) or the Health Insurance Portability and Accountability Act of 1996 (HIPAA). On the other hand, some hesitancy to interact with SwASD may stem from misconceptions about the disorder. White et al. (2019) found that individuals who did not know anyone with ASD often drew from larger social stereotypes about disability, leading them to assume that those with ASD had more severe cognitive deficits than actual symptomatology; this contributed to less positive attitudes and more biases toward their peers with ASD. However, ignorance cannot be an institutional barrier to success. Cox et al. (2021) and White et al. (2019) call for all members of college staff to engage in critical conversations with ASD students to end the misunderstanding, stigmatization, and exclusion that hinders integration and acceptance of this population.

Outside of the classroom, a student with ASD must face challenges relating to various

aspects of 'college life,' including independent living, socializing, and encountering traumatic or victimizing events. The social aspects of campus life are a common topic for postsecondary ASD literature. Researchers have found that SwASD required support in cultivating daily life skills, ranging from maintaining schedules of basic functions such as regularly eating, to managing roommate conflicts, to navigating transportation between their classes and residence (Gobbo & Shmulsky, 2014, Cullen, 2015). It is worth noting that Viezel et al.'s (2020) review of ASD-focused support programs found that only 30% offered "independent living support" such as on-call residential support to assist students in this area (p. 236). The authors suggest that this may point to a larger institutional-level assumption that SwASD are relatively independent and do not need accommodations or extra support in this area, despite evidence to the contrary emerging in the related literature (Viezel et al., 2020).

Socialization outside of the classroom can become a flashpoint for a student with ASD. Despite stereotypical depictions of SwASD as anti-social, this population desires healthy social interactions with their peers. Having a positive social life may be even more crucial for SwASD as healthy social interaction can help strengthen their social communication skills and combat the social isolation, anxiety, and depression that can occur during the tumultuous transition from high school to college (Viezel et al., 2020). Several issues can complicate the act of meeting peers and making friends on campus. First and perhaps less well known is anxiety: anxiety is estimated to be a comorbidity in 40% of cases of ASD. Students with both autism and anxiety often express the former in atypical ways that may be challenging for non-neurodivergent students to encounter, such as irritability or increased ritualistic behavior (Zaboski & Storch, 2018 & White et al., 2016). In addition, having multiple minoritized identities can raise questions for SwASD about where and how they feel comfortable socializing. One example concerning these intersecting identities is that SwASD are "more likely to identify as gay and lesbian in their sexual orientation and as transgender or genderqueer in their gender identity compared with neurotypical peers" - thus, students who identify as being on the autism spectrum and the LGBTQ+ spectrum must grapple with where they can 'come out' with their multiple identities (Nachman et al., 2020, p. 104). SwASD experiencing these moments of intersectionality may feel "invisible," have a difficult time navigating social spaces and situations with other LGBTQ and/or autistic students and are at a higher risk of being marginalized for these multiple identities - and the way in which they "highlight or downplay" them - in various situations (Nachman et al., 2020, p. 105). These identities, and the general symptomatology of ASD, may contribute to autistic students becoming socially isolated (33% of SwASD experienced exclusionary behavior in college), prone to experiencing victimization (SwASD reported higher

rates of unwanted sexual contact than non-disabled peers), and vulnerable to bullying (33% of SwASD said they did not feel safe in their classroom) (White et al., 2011, Brown, Vallejo Peña & Rankin, 2017, DeNigris, Brooks & Obeid, et al., 2018).

Supports & Solutions for Students with ASD

When considering supports and solutions for SwASD, it is crucial that practitioners remember that their role “is to help students navigate these challenging and complicated moments in ways that do not minimize their multidimensional lives”: no two SwASD will be exactly alike due to the heterogeneous nature of autism and identity (Vallejo Peña et al., 2016, p. 92). Institutions must be aware of potential fallacies in their assumptions of the desires of this student group and plan their services based on the voices of the students they serve. Listening to stories is key to understanding an individual’s intersectional personhood as well as a crucial aspect of connecting students with the best resources for their unique situation. One way to begin these listening-forward conversations is to help SwASD define what success would be for them during their postsecondary period. Accardo & Bean et al. (2019) found in their interviews with SwASD that the most common markers for success were earning a high grade point average, building awareness of self and identity formation, engaging in campus activities or organized social activities, and fostering relationships with professors and peers. These four identified areas can be serviced in multiple ways (see Table I).

Table I: Common Markers for Success in SwASD and Their Correlating Supports

Marker for Success	Correlating Supports & Accommodations
Earning a high grade point average (GPA)	Academic accommodations though a disability center (advisor, tutors, course notes, allowances for assistive technology, modified testing procedures)
Building awareness of self and identity formation	Strengths-based approach for staff/faculty (highlighting and nurturing the traits of SwASD that positively align with higher education)
Engaging in “campus activities” or “organized social activities”	Program-sponsored supervised social events, social groups, self-advocacy training, vocational support
Fostering relationships with professors and peers	Peer and/or faculty mentoring, opportunities to engage in intergroup dialogues, functional updates to traditional college life events (for example, orientations) to make them more ASD-friendly, ASD training for faculty & staff

Academic support for students with autism typically consists of accommodations and support services. Academic accommodations though a disability center may include an advisor, a tutor, receiving copies of notes, allowances for assistive technology or modifying testing procedures, all of which are generally well received by SwASD (Accardo & Kuder et al., 2019, Accardo & Bean et al., 2019). Support services vary much more by the institution and often integrate a social aspect in such programming, including supervised social activities, peer or faculty mentoring, and vocational support (Accardo & Kuder et al., 2019, Viezel et al., 2020). Accardo & Kuder et al. (2019) and Accardo & Bean et al. (2020) found in their research that despite the prevalence of social-emotional support services for ASD students on campus (i.e., peer mentoring, social groups, self-advocacy training), students with autism were generally uninterested in participating in them or ranked them as least preferred among other support services, despite otherwise being interested in socially engaging at their institution. This suggests a need to revisit how these programs are packaged and delivered to students with ASD, as helping SwASD improve their social and communication skills is necessary for them to reach their goals in and out of the classroom (Accardo & Bean et al., 2020).

One potential method for assisting this population with their identity development is by adopting a strengths-based approach. Literature in this area often focuses on the 'deficits' of students with autism. However, Cox et al. (2021) argue that the "characteristics of autism could be viewed as strengths if they were not devalued within socially constructed environments" (p. 255). Indeed, individuals with autism possess many strengths that make them right at home in academia: their restricted area of interest may support the specialized knowledge that comes with a major or graduate-level study; they are often described as intelligent; their keen desire to analyze details and gain accurate knowledge lends itself to research skills; and they work well within the clear rules and structure often found in organized classroom settings (Viezel et al., 2020, Gobbo & Shmulsky, 2014). Viezel et al. (2020) argues that these features can position students for success in college and make their areas of challenges more manageable if they are highlighted by faculty and nurtured by staff, accommodations, and support programs.

Multiple authors advocated for institution-wide change to support students with autism in their goals to positively engage with their campus, peers, and faculty. Cox et al. (2021) and White et al. (2019) criticized the institutional paradigm that expects students to completely adapt to their institution, rather than the institution (and its staff) adapting to their specialized needs. It is reasonable for institutions to expect SwASD to prepare socially, emotionally, and

academically for the transition to college. On balance, White et al. (2019) argue that it is equally reasonable for a student with autism to expect that their institution will not only “provide appropriate academic accommodations” but also plan for “campus wide acceptance and opportunities for social integration and more quality contact between students with and without disabilities,” thus ensuring a safe environment for the student to learn and live alongside their neurotypical peers (p. 2704). These support opportunities for SwASD might include opportunities to engage in intergroup dialogues or functional updates to traditional college life events (such as orientation) to make them more ASD-friendly (White et al., 2016, Cox et al., 2021). Institutions must also consider support interventions that do not directly involve the student or disability office staff, but rather all the other groups that interact with them - for example, regular faculty training on neurodiversity topics to improve ASD student-faculty interactions, or “incorporation of disability policy discussions into classroom lectures” to reduce the stigmatization of these students (Cox et al., 2021, p. 267). “Acceptance and change in attitudes will only come about when individuals with disabilities are routinely served by universities,” but this requires system-wide change on all levels to ensure that all institutional support systems are strong enough to allow students with autism to confidently “navigate the higher education landscape, find a sense of belonging, and successfully graduate from the institution” (White et al., 2019, p. 2704, Cox et al., 2021, p. 261).

Suggestions for Future Research

While the literature on postsecondary education for individuals with autism is growing, many areas remain unexplored. Investigating these questions is not only crucial for practitioners, but also for SwASD and their families who are preparing to transition to college and need this information to navigate the complex landscape of higher education accessibility. One potential area for further research is creating a comprehensive inter-university database for practitioners working with SwASD to connect, compile data and share analysis of best practices at their institution. There is a rapidly growing institutional interest in providing such resources: a study in 2016 yielded thirty autism-specific college support programs (Barnhill, 2016). Just four years later McDermott & Nachman (2020) listed seventy-four colleges offering such programs in the US. Though this rapid growth is promising it is worth noting that Viezel et al.’s (2020) research process, which included a vetting process to confirm each program’s operational status, yielded only fifty-five active ASD support programs. This suggests that some programs in McDermott & Nachman’s (2020) listing were inactive or discontinued despite being posted online (see Table II).

*Table II: College Support Programs for SwASD Growth & Change Over Time**		
	Barnhill, G. P. Supporting students with Asperger syndrome on college campuses: Current practices.	Viezel, K. D., Williams, E., & Dotson, W. H. College-Based Support Programs for Students with Autism.
Year Published	2016	2020
# of Active College ASD Support Programs Identified	30	55
% of Programs Offering Social Skills Group	50.0%	36.3%
% of Programs Offering Group Therapy/Counseling	17.0%	29.0%
% of Programs Offering Social Events	57.0%	30.9%
% of Programs Offering Tutoring	97.0%	9.0%
% of Programs Offering Life Coaching	80.0%	10.9%
% of Programs Offering Peer Mentoring	73.0%	49.0%

**Only overlapping data between the two studies has been included in this chart*

Despite the growth in programming, multiple researchers found that few universities in their studies reported collecting data on the outcomes of their programs and many institutional offices/programs were simply unreachable even for their highly organized research teams (Barnhill, 2016, Viezel et al., 2020, Accardo & Kuder et al., 2019). Few rigorous, quantitative research designs for programs created to serve SwASD are available: only an estimated seven or eight programs have been externally evaluated (Cox et al., 2021). In addition, published data on SwASD has been largely qualitative and based on small sample sizes (see Table III). 62% of

studies of SwASD in this review had sample sizes smaller than 30. Though there are no exact sample size requirements for research, small samples prevent extrapolation and may cause discrepancies in comparing data across studies (Faber & Fonseca, 2014). All future data in terms of types of service, outcomes, post-graduation tracking, or even just how many SwASD are served at each institution could make a significant difference in shaping ASD support programming at the postsecondary level (Lombardi, Rifenbark, Monahan, Tarconish & Rhoads, 2020).

Additionally, there is a great need for further research on SwASD's intersectional identities. The reflex to “isolate the identity and oppression, and not fully... understand the complexities of an intersectional lived experience” is problematic both in research and in practice and can have unintended negative consequences for students who are receiving services based on a singular aspect of their identity (Vallejo Peña et al., 2016, p. 90). SwASD often struggle with other mental health diagnoses while simultaneously navigating the racial, ethnic, gendered, sexual, and socio-economic aspects of their personhood, making them “multiply-burdened” and further compounding the challenges they face in college (Nachman et al., 2020, p. 104). Literature on SwASD who identified as LGBTQ+, female, or as an ethnic/racial minority was scarce if not altogether nonexistent in higher education publications. On average, the participant demographics of the studies that focused on SwASD (8) were 65.3% white and 74% assigned male at birth (see Table III). Higher education professionals should examine these underrepresented populations to discover how autism, its challenges, and its strengths are impacted by privileges and/or forms of oppression. These efforts may challenge the stereotype of SwASD as solely white males, as well as give practitioners more specialized insight on how to best support the entire student rather than a single aspect of their identity.

Table III: Students with ASD Study Participant Sample Sizes & Demographics

Study Title	Authors	Sample Size	% White Identifying	% Assigned Male at Birth
Disability Identification and Self-efficacy Among College Students on the Autism Spectrum	Shattuck, PT, Steinberg, J, Yu, J, Wei, X, Cooper, BP, Newman, L et al. (2014)	120	83.0%	85.0%
Aided by Extant Data: The Effect of Peer Mentoring on Achievement	Lombardi, A., Rifenbark, G.G., Monahan, J.,	24	Not Disclosed	58.3%

for College Students with Disabilities	Tarconish, E., Rhoads, C., (2020)			
Navigating Challenges to Facilitate Success for College Students with Autism	Cox, B.E., Edelstein, J., Brogdon, B., & Roy, A. (2021)	8	100.0%	100.0%
Bullying and Identity Development: Insights from Autistic and Non-autistic College Students	DeNigris, D., Brooks, P.J., Obeid, R. et al. (2018)	22	86.0%	54.5%
College Access, Success and Equity for Students on the Autism Spectrum	Accardo, A.L., Bean, K., Cook, B. et al. (2019)	48	83.0%	86.0%
College Students on the Autism Spectrum: Prevalence and Associated Problems	White, S. W., Ollendick, T. H., & Bray, B.C. (2011)	13	69.2%	62.5%
Accommodations and Support Services Preferred by College Students with Autism Spectrum Disorder	Accardo, A.L., Kuder, S.J., & Woodruff, J. (2019)	23	Not Disclosed	87.0%
Unwanted Sexual Contact: Students With Autism and Other Disabilities at Greater Risk	Brown, K.R., Vallejo Peña, E., & Rankin, S. (2017)	158	39.2%	74.0%

Finally, the current canon of postsecondary SwASD literature could greatly benefit from an examination of the impact of successful autistic representation on campus or mentoring from ASD-diagnosed faculty and staff on their SwASD. Mentoring has shown promising results for other minority student groups such as people of color and LGBTQ+-identifying people, and in general people with ASD have shown to benefit from some form of mentorship; however, little has been done to observe the potential effects of a successful faculty or staff member with autism mentoring a college student with the same diagnosis (Cox et al., 2021, Lombardi et al., 2020). This form of mentoring could potentially take the place of less desired neurotypical peer mentoring and may be more appealing to SwASD who want a deeper relationship with a knowledgeable faculty member who shares their specific interests (Accardo & Bean et al.,

2019). This may be challenging to execute as there are no statistics available on how many faculty members may have ASD, but Kaupins, Chenoweth & Klein (2020) speculate that faculty with ASD “represent a percentage that is greater than the general population due to work activities that are more compatible with such individuals” (p. 534). Facilitating a mentorship or role modeling relationship between faculty/staff with ASD and SwASD may lead to positive outcomes both academically and socially for students.

Conclusion

The population of college SwASD will continue to grow in the years to come, and institutions must prepare for the future needs of these students. Student affairs practitioners must consider how their approach to SwASD can “challenge normalcy,” “change our thinking on one-dimensional services,” and shift away from a deficit-based approach to focus on SwASD’s positive contributions to their campus community (Vallejo Peña et al., 2016, p. 93). It is the responsibility of a higher education institution and its staff to understand this unique population, identify challenges, seek solutions, share outcomes, and continue to improve existing services based on emerging research. Colleges, postsecondary practitioners, and their students with ASD should not just settle for access: together, they can strive for success.

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