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## Exploring Student Diversity: College Students Who Have Autism Spectrum Disorders

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# Exploring Student Diversity: College Students Who Have Autism Spectrum Disorders

## **Cover Page Footnote**

My dissertation, from which this article is derived, was funded in part by the Organization for Autism Research's graduate research grant initiative.

# EXPANDING STUDENT DIVERSITY: COLLEGE STUDENTS WHO HAVE AUTISM SPECTRUM DISORDERS

MONIQUE N. COLCLOUGH, PH.D.

## INTRODUCTION

Research on the prevalence of autism spectrum disorders in education is longstanding, albeit almost exclusive of the first-person experiences of college students. Two- and four-year institutions each report 2% of the surveyed student body self-identify with autism (U.S. Department of Education, 2011). The literature does not capture the first-person experiences of college students who have autism at the same prevalence of K-12 students on the spectrum. This gap limits the basis by which colleges and universities can meet the student development and academic needs of this diverse body of scholars. Because of this gap educators should be cautious about assuming that college students who have autism are homogenous, instead recognizing

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the diversity in student ability, need, and educational experiences. To capture the experiences of collegiate life in the context of college students who have autism, this phenomenological study focused on the social experiences that encourage persistence in college.

Specific to higher education, approximately 80% of students with autism attend community colleges (Wei et al., 2014). Actionable information on how to support college students who have autism that is driven by personal narratives is largely missing from postsecondary education literature. The existing literature focuses heavily on quantitative data regarding matriculation, and narratives from accessibility support services staff (Brown & Coomes, 2016). Also missing from the literature is discussion about how college students who have autism navigate the social idiosyncrasies of college life, specifically those idiosyncrasies that influence persistence and retention, particularly peer interactions, the role of faculty and/or staff mentoring, and readiness for career and/or workforce opportunities. National Longitudinal Transition Study data shows that within eight years of high school graduation young adults who have autism matriculate to higher education as both community college and university students (Roux et al., 2015). Specifically, almost 46% of young adults solely enroll at a community college, while approximately 24% of young adults attend both a

community college and a four-year institution during their post-secondary career (Roux et al., 2015). Understanding the social experiences of college students who have autism could spotlight K-12 transition planning and positively impact retention, providing persistence strategies for higher education's response to this emerging body of college students (Kelley & Joseph, 2012).

## **THEORETICAL FRAMEWORK**

Encouraging the exploration of student development theory beyond anecdotal references, Astin's (1999) work on involvement and student development theory birthed the framework for examining the relationships among persistence, student involvement, and success. Identified by Astin as a "unifying construct" (1999, p. 527), student development theory provides the foundation for student life/success initiatives, inclusive of persistence and retention. Among several environmental components that can shape a student's college experience, and subsequently retention, are participation in campus athletics, honors programs, undergraduate research opportunities and faculty mentorship, and being involved in student leadership or government. These environmental factors are important to note as they provide context for college student campus engagement.

Engstrom and Tinto (2008) expand on Astin's (1999) work by explicitly linking institutional accountability to student access, equity, and success. Writing about student persistence and retention for low-income students Engstrom and Tinto offered that learning communities could serve as spaces that help low-income students foster social engagement with peers. Engstrom and Tinto's assertion about learning communities and institutional commitments can also be transposed to the diverse community of college students who have autism. The Asperger Initiative at Mercyhurst University (Carlotti, 2014) accomplishes this through a living and learning community for 25 students in a residential setting. The Asperger Initiative facilitates social events, and a student support group led by a graduate student mentor, further supporting student persistence and completion at Mercyhurst.

## **SIGNIFICANCE OF THE STUDY**

Institutions are accountable for their environment related to preparedness and appreciation of diverse learners. The environment college students with autism are asked to adapt into needs improvement to support and develop positive social experiences. Less than half of the institutions that provide generalized accessibility support services also provide engagement and social support services (Brown & Coomes, 2016). With approximately 80% of college students who have autism pursuing post-secondary education at community colleges at some point, we must acknowledge and strategically support college students with diverse cognitive and social abilities, encouraging their involvement and subsequently their supporting persistence and retention (Couzens et al., 2015; Engstrom & Tinto, 2008; Longtin, 2014; Milem & Berger, 1997).

Understanding the social experiences and perceptions of interactions with peers, faculty, and administrators for college students who have autism is the first of many steps in strengthening the student experience. Understanding how adult learners navigate scenarios where social capital is at stake provides context for their future work environment, influencing outreach, and programs created for career preparation (Wehman et al., 2014).

## METHODOLOGY

Qualitative inquiry, specifically this study's phenomenological design, records the diverse lived experiences, backgrounds, and identities of the study's participants. As an alternate to the deficit approach of research centered on the challenges or accommodations of college students with autism, this person-first descriptive study explored the social experiences of college students who have autism and the impact of these experiences on persistence and retention (Chown & Beaven, 2012; Gobbo & Schmulsky, 2012, 2014; McKeon et al., 2013). The following research questions were a guide to the study: What are the social experiences of college students who have autism? What role(s) do various social experiences play in the persistence and retention of college students who have autism? As previously identified, high school graduates who have autism attend both community colleges and four-year institutions at a rate of almost 24% (Roux et al., 2015). It is important to note this enrollment trend as this phenomenological study was conducted at a public, urban, research-intensive, doctoral-granting institution in the southeastern United States during fall 2015 and spring 2016. To address exclusion, the inclusion criterion for the sample population was self-identification with autism for enrolled students and recent college graduates who completed degrees within the previous six months. Undergraduates who self-identified with autism spectrum disorders were invited to participate in semi-structured interviews by way of campus advertisement on the institution's daily student announcements via email, university televisions located throughout the student center and academic spaces, partnership with regional autism advocacy organizations, and the institution's accessibility support services staff. The sample site was selected as a result of the diversity in course delivery for both non-degree and degree-seeking students, which tend to appeal to diverse learning needs (Remy & Seaman, 2014).

### Data Collection

During fall semester 2015, almost 800 undergraduate and graduate students were registered with the sample site's Office of Educational Accessibility, of which 3.5% or approximately 28 students self-identified with autism and/or Asperger's Syndrome. After Institutional Review Board (IRB) approval, potential participants were recruited through the Office of Educational Accessibility, campus advertising through student and faculty announcements, and collaboration with several on- and off-campus partners also working with students who have autism, including two regional autism societies and a national autism advocacy organization. It is important to note that other institutions have

found success in partnering with autism societies and advocacy organizations to connect with college students. As a best practice, a snowball sampling method was also used to identify other participants who met the inclusion criteria. To confirm interest in the study each interested student completed a brief Qualtrics survey after responding to the call for participants.

Beginning in fall 2015, data collection persisted until spring 2016 when saturation was met. The purposeful sampling method and snowball sampling strategy yielded five participants (N = 5) (Table 1). It is important to note that five additional students showed interest in participating in the research, but were ultimately unable to commit to participation. It is believed that the diversity in communication and social experiences, can lead to stigmas associated with autism, thereby increasing the number of participants reticent to engage in this inquiry and others (Haas et al, 2016; Shattuck et al, 2014). Additionally this study's participant yield is aligned with a mixed methods needs analysis study that also had five participants (White et al., 2016).

Semi-structured one-on-one interviews were conducted with the five participants, with the interviews ranging from 30 to over 90 minutes. Each participant was interviewed at least once, resulting in 307 minutes of participant data. Interviews were held in various locations on and off campus, including the university library, academic classrooms, and through a synchronous format, Skype. The variance in interview length reflects the diversity in participant communication styles and abilities, including those with elaborate responses, as well as a participant with speech disfluency.

Created to capture the research questions without directing the participants to focus on a singular element of their collegiate experience, 12 semi-structured interview questions were intended to be a conversation guide. The interview questions were compromised of main questions and probes (Rubin & Rubin, 2012), and included the following:

When did you begin to think about attending college?

Were there any transition plans or programs that you participated in prior to enrolling in college courses?

How do you describe your social experiences as a college student?

Do you feel engaged with the social events/offerings on and off campus?

Are there any significant success or lessons that you've learned, and if so how would you describe them?

Following the foundation of qualitative inquiry, each transcribed interview was initially analyzed using a *priori* codes developed from the literature and previous pilot study. Simultaneous data collection and analysis were used to take advantage of qualitative research's features, while intentionally identifying patterns and textural themes among the data (Miller & Salkind, 2002; Rubin & Rubin 2012).

Specifically, a *priori* codes were used to analyze and code the transcribed audio data line by line, identifying common themes, pertinent participant quotations, and unique language, creating patterns of loosely identified thick descriptions that were used for comparative pattern analysis. The *a priori* coding assisted in identifying etic codes or categories, expanding and revising the initial codebook, and creating narrative themes and textural data for the final codebook (Hays & Singh, 2012). The final codebook and cross-case analysis were a reflection of the comprehensive data identified throughout the data analysis, becoming the foundation for a comprehensive narrative of the diversity of student perspectives, experiences, and recommendations for supporting college students who have autism.

To memorialize salient thoughts and experiences, each participant interview was paired with a contact summary sheet, which was used to record observations and experiences immediately after each interview. Reflexive journaling also bracketed any researcher subjectivity. Confirmability was demonstrated through member checking. Two weeks after each interview an executive summary of keywords and themes, less than 500 words, in a bulleted format, was presented as a memo to each participant for their review and feedback. Responses to the memos were used as new additional data.

## Participants

Pseudonyms were used to identify the participants and protect their anonymity. The participants self-identified with autism and confirmed receipt of diagnosis by a medical professional during their educational career. The confirmation of diagnosis is important to reflect as one participant, Mary, shared that there is internal community discord amongst persons who have autism around the notions of "having your papers". Ranging in age from 19-36 years, two participants, Mary and John, attended both a community college and four-year institution during their postsecondary educational career. Notably, Don and Mary were diagnosed in adulthood and after enrollment in college courses, adding to the rich diversity of student experiences. Four participants were male, one female, and two participants identified as a person of color, i.e., Hispanic/Latino and Biracial/Multiracial, or Asian American.

**Table 1**

**Research Participants' Demographics**

<b>Participant</b>	<b>Gender</b>	<b>Race/ Ethnicity</b>	<b>Age</b>	<b>Age of Diagnosis</b>	<b>Accommodations</b>	<b>Classification</b>	<b>Prior Attendance</b>
Mary	F	White	35	33	None	Alumni	2-year College
John	M	White	26	1st Grade	Extended Time & Recording Rights	Sophomore	2-year College
Gary	M	Hispanic/ Latino & Biracial/ Multiracial	20	9 or 10	Extended Time & Quiet Testing Room	Sophomore	None
Norris	M	Asian American	19	7	Extended Time	Freshman	None
Don	M	White	36	32	None	Alumni	None

*Note:* All names are pseudonyms.

**Data Analysis**

There were seven themes in the participant narratives about their post-secondary experiences, five of which were relative to both the community college and four-year institution setting: (a) campus engagement, (b) noise, (c) faculty engagement, (d) intentional peer/classmate interactions, and (e) romantic experiences. What seems to be a simple decision to attend a campus event, as in a lecture, pep rally, or athletic event, can actually be a more complex decision for college students who have autism. “John” expressed his sentiment about campus engagement: “As it is...I go, I come here to learn. I don’t care about the sports. Never have, never will...” (John, personal communication, February 18, 2016). Half of the participants shared they are either intentionally not engaged or cautiously engaged with social events on campus, due to the size of the crowd, potential noise levels, general disinterest, and anxiety associated with being spread too thin or being unable to focus appropriately on academics. Mary shared that her decisions to attend social events are based on her sensory needs, preferences, and her position on disconnectedness with what she believes is the standard identity of an undergraduate student—that is, being incredibly social, eager to attend campus events among throngs of other people, and willing to participate in athletic events.

**Campus Engagement:** The diversity in campus engagement is further illustrated by Norris’ earnest hesitancy to disrupt the rhythm of his academic focus, which was positively influencing his persistence and retention. When asked if there were any things that he wished were different, among them taking additional Advanced Placement credits in high school, he responded that like other college students he wished he was able to get more involved on campus and simultaneously do well academically.

**Noise:** Likewise, noise was linked closely to the decision to not engage socially with campus. The decibel range at campus events and the lack of control over noise presented a concern for some participants. Mary illustrated this best when sharing two questions she asks of herself before considering attending an event: “Is there going to be a lot of noise? Okay. Am I able to manage it? If not, don’t go...if I could change anything it would be all the heavy emphasis on participating in all of these things” (Mary, personal communication, November 30, 2015). Mary can trace the conscious avoidance of noise back to her adolescence, age 12 specifically, when she began to separate herself from people and scenarios that were excessively noisy.

**Faculty Engagement:** Although intentionally reluctant and selective to engage socially, participants recall their relationships with faculty with fondness and admiration for their support of academic success in individual courses, as well as overall degree completion. Faculty engagement was a complement to intentionality concerning peer and classmate interactions. Talking with faculty often began with course content and extended to a mentee/mentor relationship as the participants progressed toward degree completion. Building connections with faculty around their major of study and academic achievements furthered student connection to campus.

**Intentional Peer/Classmate Interactions:** Don and Gary specifically talked about purposefully creating friendships to either support academic achievement or create a social identity. Familial support, connections with faculty, and friendships with other peers outside of campus were also influential in the participants’ persistence and retention. Established in a high school Advanced Placement program, Gary was a member of a group of three who built an intentional academic and social support network as college students: “...we just help each other out, you know, like we’ll help each other study...” (Gary, personal communication, February 18, 2016). Don’s creativity led him to develop a campus-based disc jockey radio show dedicated to disco music; sharing his goal to be extreme and easily recognizable on campus in lieu of just blending in with the student body.

**Romantic Experiences:** Participants also referenced unintended romantic relationships during their college career. Although none of the students attended college with the hope or intention of meeting their significant other, sexual identity and orientation also played a role in social experience. The participants introduced the presence of romantic experiences or relationships as an element of their social interactions with peers, on and off campus. The impact of learning how to communicate, understanding social cues, and becoming aware of communication preferences was important in understanding the relationships of the participants. Two of the students recalled talking individually to women with whom they had interest and the relative ease in which a conversation or an invitation to lunch would be extended. In retrospect, the students recalled the conversations as a natural event and did not frame establishing personal or romantic relationships within the context of being a college student with autism.

## **Discussion of Findings**

College students with autism spectrum disorders face a unique array of scenarios that both directly and indirectly impact their readiness and success in higher education. First-person narratives from a body of diverse college students who have autism provide insight into the complexities of identity based on their narration, social experiences, and relationships with others. This includes identity as a college student, as a person who has autism, a person of color, and a member of the LGBTQIA community.

### **Social Experiences**

In relation to the first research question posed in this study, participants were asked about their social experiences as college students who have autism. The participants shared that in most instances they choose not to engage intentionally, due in part to the challenges noise and crowds presented at campus events. The unpredictability of a crowd's size, behavior, and decibels discourage attendance at events that are traditionally seen as the bedrock for the student experience. Astin's (1999) work on the intersection of environment, student identity, persistence, and student involvement is illustrated in the connections participants made with faculty. Likewise, the connection with faculty appears to build a foundation of support and affirmation that encourages persistence, personal exploration, and academic growth (Milem & Berger, 1997). An interpretation of Astin's (1999) work identifies the forgotten essence of his contribution to student development theory, which is engaging with and experiencing campus life, and those experiences becoming the foundation for a student's expanding adult identity.

In a broader context, the participants' social experiences were inclusive of intentionally crafted and maintained friendships with people off campus, collegial friendships with faculty, and romantic relationships. The participants did not use campus as their hub for communication, connection, nor identity, yet were still having incredibly valuable social experiences as college students who have autism. It is unknown if the intentional disconnect with campus was due in part to the complex nature of autism itself, or, if the disconnect was the product of a lifetime of being forced to engage with environments that do not take into account diverse abilities and needs (Ne'eman, 2010).

Student frustration with this expectation is evident as stated by John:

There's all of these expectations to participate in all of the stuff and these things...it's almost as if social interaction is demanded at times... and if not, uh, then people think, they'll think you're just one of those people. (John, personal communication, November 30, 2015)

### **Social Experiences Relevant to Persistence and Retention**

As evidenced by this sample population, social experiences do not appear to influence persistence and retention—answering the second research question. Four of the participants' persistence and retention is influenced by additional factors including parental support, the proximity of the institution to family,

and the opportunity to reside at home, thereby eliminating on-campus housing expenses. Although there was a natural ease each of the students described when talking with their instructors, none of the students identified faculty engagement as the primary factor in their persistence and retention. Instead, Don, Mary, and Norris described their interactions with faculty as positive influences, noting in particular the ease of conversation and relatability. John, who attended both a community college and four-year institution, shared the following:

I generally have a social relationship with most of my instructors...I walk and stay after and ask my instructor questions and sometimes that will lead to conversation that are related to the question and we kinda just get to know each other that way. (John, personal communication, November 30, 2015).

The diversity within the social experiences of college students who have autism is important and valuable to understand. While the persistence and retention of this study's participants does not appear to be influenced by their social experiences, it is critical nonetheless to understand what experiences students are having, what experiences they are avoiding altogether on campus, and the types of experiences they are creating for themselves throughout their college enrollment.

### **Implications for Practice**

College students who have autism are attending community colleges at increasing rates (Roux et al., 2015; Wei et al., 2014). Because of this, community colleges are rich opportunities for strategic degree completion initiatives, strategic workforce development, and baccalaureate transfer pathways. Institutions are accountable for their environment related to preparedness and appreciation of diverse learners. True to institutional mission, community colleges represent opportunities of access and equity for college students who have autism. A question worth exploring: how can community colleges (which often have restrictive budgets) prepare for, and respond to, the rich diversity within this body of students?

Peer institutions across the country have responded by partnering with regional advocacy groups. As an example, Howard Community College partners with the Howard County Autism Society on Project Access, a K-12 initiative that creates a seamless transfer experience for high school students. Montgomery Community College collaborates with the Maryland Division of Rehabilitation Services to facilitate the DORS-Pathways Program. Here in the Commonwealth of Virginia, Virginia Commonwealth University has partnered with community colleges in the Tidewater region to meet the needs of students participating in the ACE-IT in College program. What other collaborative efforts can be explored to strategically attract, retain, and credential college students who have autism?

As described by students who attended both community colleges and universities the role of faculty connections influences the collegiate experience. Conversations

with faculty add to the cultural experiences of college students with respect to their autism identity and any other comorbid diagnosis. With the proliferation of well-crafted first-year experience (FYE) initiatives and community college to university bridge programs it is unclear what influence that earlier summer connections to faculty advisors could have on further familiarizing college campus culture, reinforcing purpose, and academic identity. Similarly, the participants discussed disability services, almost exclusively to provide accommodations, yet their role in the persistence and retention of college students who have autism can be explored more explicitly (Robertson, 2010). Specifically, what type, if any, of case management techniques do disabilities services staff provide students who are on the autism spectrum?

Lastly, an opportunity for college response exists in the creation of peer support or social groups for college students who have autism. Recommendations for a peer support or social group include having a staff member lead the logistical/administrative output, in part because students would fail to stay organized or motivated long term. There are institutions that have peer-facilitated groups as a safe space for students to socialize and develop friendships or explore romantic relationships (Carlotti, 2014). As best practices on how these groups function are identified institutions must inquire internally, how, and if, they are encouraging the development of social capacity that will provide context for job searches and employment (Wehman et al., 2014).

## **CONCLUSION**

This research study was purposefully created to capture the voices of college students who have autism spectrum disorders, focusing on the strengths and layered diversity within the autism community, instead of approaching differing ability from a deficit lens. To do this, two research questions were developed: What are the social experiences of college students who have autism? What roles do various social experiences play in the persistence and retention of college students who have autism?

Although the five participants were recruited at a public university in the southeast, two participants began their post-secondary career at a community college. Their enrollment affirmed that within eight years of high school graduation, young adults who have autism matriculate to higher education as both community college and university students.

In most instances the participants chose not to engage with campus-based social experiences due to challenges that noise and crowds presented. Yet, the participants intentionally developed social connections outside of campus with friends and family. It is these social connections that appear to influence college student persistence and retention. Equally instrumental, participants recognized the positive impact college faculty had on their undergraduate experience, self-confidence, and awareness as students and alumni. As access to post-secondary education continues to expand, the study's findings present opportunities for further research into retention and institutional support for community college students who have autism spectrum disorders. Opportunities for additional research into the professional development of community college

accessibility services staff in supporting college students who have autism, and the professional development of faculty who will teach and advise community college students with differing abilities and career development goals exist.

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### **ABOUT THE AUTHOR**

Monique's scholarship examines neurodiversity in higher education, focusing on college students who have autism and their collegiate experiences.