

THE AUTISTIC COLLEGE EXPERIENCE: AN AUTOETHNOGRAPHIC STUDY

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Abstract

This thesis considers the autistic college experience from an autoethnographic perspective. It critically examines my own experience as an autistic person, how autism has shaped my life in college, and the evolution of my self-identity in relation to autism. Further, I contextualize this with the documented journeys of other autistic college students, gathered from qualitative studies, anthologies, and other sources, and from my interviews of college students at my university. With this, I demonstrate how I have evolved from seeing my autism as a condition separate from my personhood to an essential part of who I am. Finally, I use the information synthesized from my experience and my research, to recommend supports for autistic students at the university level.

Key words: autistic college students, autistic identity, autoethnography, higher education, autism, neurodiversity

Table of Contents

Introduction and Literature Review.....	5
Method.....	8
Step 1: Reflecting on My Experiences with Autism and Schooling, including College	
Step 2: Learning From Published Accounts of Former Autistic College Students	
Step 3: Learning From Fellow Autistic Appalachian State Undergraduates	
Step 4: Reflecting on What I’ve Learned	
Results	
Finding My Autistic Identity.....	11
My Early School Experiences	
Success in Middle and High School	
My College Experiences	
Changing My Major and Career Path	
Comparing and Contrasting My Experiences With Other Autistic College Students Experiences.....	18
Diagnosis Leads to Self-understanding	
Masking and Unmasking	
Acceptance	
Embracing Autistic Identity	
It’s a Choice to Identify as Autistic or Not	
Variability of Support and Resources in College	
Having Supportive Friends	

Self Advocacy	
Discussion.....	30
Suggestions for Supporting Autistic College Students	
Offer a Neurodivergent Residential Learning Community	
Provide Single Rooms in Residential Housing	
Having a Place to Go to Decompress on Campus	
Limitations	
My Blind Spots Because of Early Diagnosis and Support	
Autism is a Spectrum	
Potential for Different Insights from a Larger Scale Study	
Conclusion.....	37
References.....	40
Appendix.....	43

The Autistic College Experience: An Autoethnographic Study

My initial inspiration for this project came from a literature review I completed for a special education research course I took in my sophomore year. As an autistic college student myself, I wanted to understand how this population could be better supported. My two research questions were:

1. What are the reported social and emotional needs of autistic college students?
2. What are the effects of social and emotional interventions intended to help autistic college students succeed?

With regard to my first research question, I found that autistic college students' challenges are not dissimilar to those of their non-autistic peers, but often they are heightened, more persistent, and require greater effort to overcome. Work-life balance and making time for academics as well as relationships were among the struggles reported by students (Bailey et al., 2019). Emotional regulation, executive functioning, and adaptive skills are areas of frequent struggle for autistic students, which they are assumed to have mastered based on standard college accommodations (Zeedyk et al., 2019). Limited understanding on the part of faculty and staff can also be a barrier, as can students' lack of understanding of their disability or awareness that they are autistic (Accardo et al., 2019). Ultimately, autistic students are given more independence than they have had at any prior point in their lives and are expected to navigate the college environment self-directed with few specific accommodations, and with faculty and staff who have varying degrees of knowledge/awareness of any students' disabilities.

In response to my second question regarding social and emotional support, I learned

that some peer mentorship programs have shown efficacy, particularly when mentors were perceived as friends that autistic mentees could make personal connections with (Thompson et al., 2017). Closer and less formal relationships with mentors were correlated with greater benefit from the programs (Thompson et al., 2020; Roberts & Birmingham, 2017).

Something one student expressed liking about a mentorship program was "... being able to express my thoughts about any issues I may have. (Ames et al., 2015, p. 33)." Autistic students also tended to benefit more from programs centered around self-advocacy than social skills (Gillespie-Lynch et al., 2017). Academic goals overall were more important to autistic students in the beginning of the college experience, but after those were met, they appeared to consider pursuing social goals as well (Roberts & Birmingham, 2017). Across all of these studies, the development of relationships was most critical to the success of the programs.

These studies demonstrate the value of relationships and peer mentorship in helping autistic students navigate the college system. However, such programs put an impetus on students already knowing their wants and needs and teach them to navigate college as it is. Noticeably, there was a lack of research on a systematic level to make college more accessible to autistic students.

Importance of Autistic Participation in Research

Incorporating the autistic voice allows for more authentic and nuanced insights into the autistic experience. My journey as I have analyzed it in this thesis, the literature and anthologies I have read, and the survey and interviews I have conducted with fellow autistic college students bring that insight to this project. They shift its grounding from a non-autistic

idea of an autistic success story to success in college measured by the goals and aspirations of autistic students themselves.

Autistic participation in research is critical because many of the things that autistic students struggle with are not understood by people who are not autistic. Autistic struggles are relatable to experiences that all people have, but not entirely the same. Autistic participation in research is important because it validates autistic perspectives. Many autistic people are fully capable of speaking for themselves, and know what their needs are better than individuals whose brains do not function as theirs do.

Value of Autoethnography

To understand what it means that this paper takes an autoethnographic approach, one must have a working definition of autoethnography. In short, it is a research method that seeks to identify and understand culture, beliefs, and the world through the lens of personal experience (Adams et al., 2017). Autoethnography requires deep reflection upon one's personal experience as a member of the group they are studying, and makes connections to a social, political, or cultural context beyond the individual researcher (Adams et al., 2017).

The roots of autoethnography can be traced back to the 1980s, as researchers began to interrogate traditional methods, acknowledge the limitations and biases that come with outsiders looking in on a group, and emphasize the importance of personal stories and narratives (Bochner, 2014 as cited in Adams et al., 2017). As a research methodology, autoethnography demonstrates that people within a group have unique insight, the effect of which cannot be replicated from the outside looking in (Adams et al., 2017). The goals of autoethnography are to, first, counteract negative commonplace ideas, cultural scripts, and

stereotypes (Boylorn, 2014 as cited in Adams et al., 2017), second, to capture cultural experiences from an inside perspective, and, lastly, to write for an audience beyond academia (Adams et al., 2017).

As an autistic college student, my position itself contradicts dominant cultural scripts and stereotypes about autistic people. In my years of searching, I have been able to find little research on the autistic college experience, and for this purpose, I decided to pursue an autoethnographic study in which I share my story, how it intersects with other autistic peoples' stories, and what that means for the autistic college experience. As an autistic college student myself, I have a unique opportunity to connect my personal experience with the experiences of others and emerging research to come to an understanding of how autistic students can be better supported.

Method

As autoethnography has flexible methodology, I would like to describe my approach in completing my autoethnographic study on how colleges and universities can better support autistic college students:

Step 1: Reflecting on My Experiences with Autism and Schooling, Including College

I provide a version of this reflection in the Results to give the reader a sense of who I was before I embarked on this journey as well as on how the journey transformed me. This is vital, as I would like the reader to feel as though they are experiencing this story from my perspective. After completing steps 2 and 3, I revisited my reflection and added comments to help contextualize my experiences based on the comments of other autistic students I had read or interviewed.

Step 2: Learning From Published Accounts of Former Autistic College Students

As one person, my experience is unique. It can offer special insight, but as it is unique, it is not universal. By considering the experiences of others, I hoped to gain valuable insight into the experience of autistic college students and further hoped to identify a range of practices colleges could use to better support them. I gleaned particularly enlightening insight from two anthology books: *Aquamarine Blue 5: Personal Stories of College Students with Autism* (a collection of essays from then current and former autistic college students edited and including one essay by Dawn Prince-Hughes in 2002), and *Navigating College: A Handbook Written for Autistic Students From Autistic Adults* (Ashkenazy & Latimer, 2012) published by the Autistic Self-Advocacy Network.

These resources, (Prince-Hughes, 2002; Ashkenazy & Latimer, 2012) were beneficial for me in terms of understanding the struggles of other autistic students as they presented first-hand accounts written by autistic adults. Reflecting my own experience, they demonstrate the importance of self-advocacy at the college level, which not all autistic students are aware of going into college.

Step 3: Learning From Fellow Autistic Appalachian State Undergraduates

I conducted a survey and interviews with current students at Appalachian State University (App State) to gain insight into their college experience. I felt this was important so that I could contextualize my experience within those of people around me, as this is an autoethnography.

Using snowball sampling, I emailed a Google Form with questions about their experience to App State students I knew who had an autism diagnosis. I shared an email with

my committee members so that they could forward the invitation to fill out the Google Form to students with an autism diagnosis that they knew. See Appendix for the questions I asked in this Google Form. For those survey respondents who indicated they would be interested in a follow-up interview over Zoom, I reached out via email to schedule a time. This research was deemed exempt from IRB review. However, I took steps to protect my participants, including using pseudonyms when discussing with my committee and in the essay.

Three students responded to the survey and two participated in follow up interviews where they elaborated on their responses to the survey and provided additional insight. Student A completed the survey only. Student B and Student C completed the survey and follow-up interview. I recorded and transcribed the interviews for further analysis. After I gathered all of the survey responses and transcribed all of the interviews, I put Student A's survey in one document, Student B's survey and interview in another, and divided Student C's survey and interview into two documents as my interview with her was significantly longer than with Student B. I created charts in two separate documents, one to note themes of similarities and the other for themes of differences from my experience. As themes emerged I put them in the tables and quotes that supported those themes under each. I then kept those themes in mind as I analyzed a more recent metasynthesis of qualitative literature (Irvine & MacLeod, 2022) looking for elaboration on those themes or the emergence of new ones in my research. I then used the themes I noted from my surveys and the literature review to structure my paper.

Step 4: Reflecting on What I've Learned

In the Results section, I examine the development of my identity as an autistic person

incorporating the perspectives I have gleaned from *Aquamarine Blue 5*, the *Navigating College* handbook, and the interviews I conducted with peers at App State. I also reference the studies I reviewed on the self-reported needs of autistic college students. In the Discussion section, I synthesize my experience and those of other current and former autistic college students from my survey and interviews and research and provide suggestions for universities working with autistic college students to consider. I discuss what has worked for me, what has been reported to work for other autistic college students and what they would like to see, and propose ideas based on those. I also address the limitations of this study.

Results

Finding My Autistic Identity

My experience with autism, its impact on my life, and the formation of my identity around it has been complicated. Living as an autistic person has been critical in forming who I am personally, professionally, and academically. My autistic identity has evolved over the course of my life, shifting most critically in my college years. When I was young, I saw it as a challenge that I needed to overcome, it was something that prevented me from making friends, and got me in trouble for disrupting class. I did not see it as a part of who I am. As I have come into my own, however, I have been able to work on my difficulties and advocate for myself and other autistic people. When I was younger, I only saw my deficits, and how they impaired my education and relationships. With those challenges overcome and the perspective I have gained as an adult, I now realize the ways in which autism is a part of me, and this understanding guides me to help myself and other autistic students find personal, professional, and academic fulfillment.

My Early School Experiences

My early school experiences were different from those of my peers. From first through third grade, I was a social outcast, and found it difficult to regulate my senses and emotions. My first three years of school were awkward and uncomfortable. It was difficult for me to make friends because I did not understand how to socialize with them, and I would stim in ways that were disruptive to others. I could not regulate the environment, but could not verbalize that struggle. Similar to early childhood experiences described by autistic university graduate Garry in *Aquamarine Blue 5*, “I did all the usual things at much the same time as my age group... I did not show any interest in socializing with other children (Garry, 2002, p. 3).” I was also like Garry in that I could be intensely enamored by my special interests, which in those early years of my life included Transformers, Star Wars, and Spider-Man. My peers liked some of these things, but my interests were particularly intense and I frequently talked about them beyond the point to which my peers were able to continue. Garry described his experience pertaining to his relationship between friends and special interests similarly, “Sadly, because of these traits, and not being interested or able to do the same things as my peer group, I had no memories of having friends and bonding with them (Garry, 2002, p. 4).” I was generally more interested in talking about things and ideas than daily life or people, which disconnected me from my peers.

It was difficult for me to transition to the school setting and realize that the classroom was not an appropriate time to play or talk about things that were not related to school to the extent I did. I was diagnosed with autism at age seven, and I have known about my diagnosis since I received it. Up until the third grade the teachers and administrators tried to help me

succeed, but they did not fully understand me. I do not remember much about these years, but I remember feeling alone, unwanted, and ashamed of myself. My parents fortunately, educated themselves about autism and advocated for me during this time, and at home I felt cared about, which is not always the case. As Student A described, “I did not feel accepted as an autistic person in my home because my parents just have a hard time believing it.”

This makes me wonder what research has been done exploring the role of parental acceptance of an autism diagnosis on their child’s later identity and success.

When I was in third grade I transferred to a different school. I had a very different experience there. I found teachers and administrators who understood my struggles, and were willing to help me achieve my full potential. I also found peers who accepted my differences to an extent and I was able to form meaningful relationships with them. However, these relationships often paused after school was dismissed and resumed the next school day. I initially spent a lot of time in a separate setting to finish my work and learn social and emotional skills. I formed close connections with the principal and special education teacher there, a pattern of developing closer bonds with teachers and those older than me than with my peers in age that would persist until I entered college. I also became involved in extracurricular programs such as a theater group, which helped me build a social network and find an outlet to express myself. By the time I was in 5th grade, I was virtually spending all of my time in general education. I had made many friends, and I was able to surpass many of my peers in my academic coursework.

Success in Middle and High School

This success continued throughout middle and high school. I had no difficulty making

friends, keeping up with my classes, or connecting with teachers. I was also well-liked by my teachers and administrators. I no longer felt excluded or ashamed: I felt normal. However, my relationship with my autism was complicated during this time, I was not ashamed of it, and I was open about being autistic (I would have said that I had autism at the time), but I was not exactly proud of being autistic. To me at that time, my autism was something extrinsic to my identity; something I succeeded in spite of, rather than a part of me that came with unique gifts and struggles. At that time, almost all I could think about coming from autism for me was my struggles. I treated it as a barrier that I surmounted to be as successful as I became, not a balanced guiding force in my journey.

My College Experiences

When I was beginning my freshman year, the transition to college life was difficult, particularly in the midst of a pandemic during which I had become conditioned to not going out to places and doing things. Douglas O’Neal, an astronomy and physics college teacher, described in his essay, “School was easy for me, and I would get all my work and studying done before others. Thus, I had no use for study groups, and I could not sympathize with those who had to pull all-nighters the night a test was given or a homework set was due (O’Neal, 2002, p. 87).” The lack of challenge of schoolwork and its impact on relationships that O’Neal describes aligns with mine, as I never joined any study groups and I could not relate to the experience of staying up late to work on imminently due assignments because I did not need much help, and usually finished early. When I did check in with friends, they often said they were busy with schoolwork. I understood intellectually, but it also was isolating because it felt as if I could not relate to the experiences of my peers. Similarly,

respondents in Bailey et al. (2019) reported feeling they had to trade off between academics and social life, and focusing on academics at the expense of social life was linked to lower subjective well-being. Additionally, as was highlighted by Gurbuz et al. (2019), my high academic performance could mask my early social struggles.

Another barrier was driving to go to places to socialize, which is difficult because of the effort I put into processing everything on the road. I have already spent much of my energy by the time I arrive at a place, and often come back exhausted when I drive. However, when I met a friend in the Appalachian Community of Education Scholars (ACES) and she disclosed to me that she was autistic it helped me make a greater connection around that identity. It helped me see and process these differences in experience and connect with those whose experiences were more similar to mine. I had someone to socialize with who could share and with whom I could share relatable experiences. I had a friend I did not have to make small talk with, a friend I could infodump about my special interests without having to be conscious about it, and someone who had stories to share that made me realize how much of my experience was part of my autistic experience. This was very empowering for me, as it helped me reframe my view of autism in myself as something that makes me who I am, rather than something separate from me that makes my life more difficult.

The Appalachian Community of Education Scholars (ACES) is a four-year teacher preparation program which I am in. As part of that program, I lived in the same dorms as my cohort for the first two years, and throughout I was able to bond with similarly minded and professionally directed peers through shared community-building and professional development experiences. These were all centered around education, as I began my program

as an education major. Additionally, there was a peer mentorship element, which has been shown to have potential for autistic students (Ames et al., 2015; Gillespie-Lynch et al., 2017; Roberts and Birmingham, 2017; Thompson et al., 2020). Having these opportunities to bond with a smaller group of people helped me build a social support network and learn self-advocacy while giving me opportunities to make professional connections. The connections also gave me a sense that I would see these people again, contrary to the struggle reported by Hunter in Alverson et al. (2019) that he saw no point in making friends with people he may not be able to see regularly. I am also in the Honors College, which allows me to interact more easily with my fellow Honors College classmates across several different courses.

As I moved across the years in college, I was able to find community and develop many meaningful relationships. However my friend from ACES described being somewhat of a social outcast, not being understood, and not getting the help she needed in school. This was a theme throughout my reading, particularly expressed in the experiences of individuals as described in *Aquamarine Blue 5* (Prince-Hughes, 2002). This disparity of experiences inspired me to focus more on researching the perspectives of autistic self-advocates. In doing so, I realized how much autism was not just something that I had like an illness or disorder, but rather it had a major positive impact on my life, identity, and aspirations.

Changing my Major and Career Path

Changing my major after I had my mind set on it for so long was devastating. It happened late in my program and was gut-wrenching, but as *Higher Education Transitions* in the ASAN handbook highlights it is far from uncommon for college students to change

majors (Kapp, 2013). At the beginning of my third year I had my first field experience, which I was very excited for. However, when I began, the reality of the classroom structure, and the dynamic of the school were not as I believed they would be. I did not feel welcome as an aspiring educator, and I felt a strong disconnect between myself and the staff of the school. As a result, I could not complete my placement, which put me at a crossroads for my future. Upon reflection, I realized that, although I wanted to continue in this program, there would simply be too many hurdles to jump through with remediation, delayed graduation, and no guarantee that I would be able to finish the program. Additionally, I saw that it was not the only job in which I could help people with disabilities. For all of my life in college, being an aspiring special education teacher was part of my identity, and now I was coming to realize that it may not have been what I was meant to do.

For anyone this would be devastating, but being autistic with a brain already wired for a preference for routine, it was doubly so. It was the most strenuous experience for my mental health I have had in my life thus far. The university was also not supportive of me during this time, and for the first time since the very beginning of my studies, I felt like an outsider. Cage & Howes (2020) synthesized themes of “the strain on mental health” and “outsider status” as factors in students dropping out (Cage & Howes, 2020 p. 1669). The stress of this experience was so much at times that I was on the verge of thinking as a former student, June said, “I don’t want to feel like that again. So... I just can’t do it [the degree] (Cage & Howes, 2020, p. 1669). In one instance, I tried to ask for accommodations in the beginning and the professors were unresponsive. I quickly dropped the class and while the rest of my classes were difficult, the level of challenge was not insurmountable because, as

Samantha April Davis advised in *Self Accommodation* (Davis, 2012), I learned to ask for accommodations and advocate for myself early. Thanks to the self advocacy skills I developed over the years, and the support systems I had, I was able to accept this change and embrace my new career aspirations. It was a long process that required therapy and careful discussion with people I trusted.

Comparing and Contrasting My Experiences With Other Autistic College

Students' Experiences

As I reflected on my own experience and framed it in relation to the experiences of other autistic college students, I noticed some similarities and many differences. The comparison and contrast of my experience with the experiences of others brought out powerful themes. It highlighted how diagnosis leads to self-understanding, the detrimental impact of masking and the importance of unmasking to discovering oneself. It also brought out themes of embracing one's identity and the choice of identifying as autistic or not. Finally, it demonstrated the variability of support available to autistic college-students, and the importance of supportive friends, and self-advocacy.

Diagnosis Leads to Self-understanding

Student B described being socially isolated as the 'weird' kid in high school without a diagnosis. After getting a diagnosis, Student B reported feeling, "I don't fit in with the norm, and I have a reason, which is nice." Having a diagnosis as a child perhaps helped me cope better because I knew why I was different. It also helped me have meaningful relationships with my peers because it gave me an explanation to others for behaviors they may have otherwise considered off putting. It helped that I could explain my brain worked differently

rather than simply being the “weird” kid as Student B described in their early experiences. Because of the accommodations I received, and the empathy from instructors for my diagnosis, I was able to excel academically.

Unfortunately, many autistic people are not diagnosed until they are adults, and are unable to find empathy and understanding. This is especially true for autistic people who do not fit a stereotypical image as white, cisgender, and male. Student C, who is female, reported noticing racism and misogyny in anti-self diagnosis rhetoric. A friend of Student C’s in social work classes discussed with her, a teacher, “...talking about how the Tiktokification of autism is so harmful.” However, Student C posits that “conversations condemning self diagnosis are more harmful because it takes away from conversations that actually need to be had around disability.” As Student C observed, this appears to shift the conversation toward symptoms of a problem rather than the problem itself, which is disparity in knowledge of autism in and availability of a diagnosis for women and people of color. As Student C noted, “... when trans people of color started coming out, and everyone was like, oh, there’s too many trans people now, and it has racist and misogynistic implications behind it, because when only white men are getting diagnosed, then it’s okay. But when everybody else says they’re autistic and can’t get a diagnosis, then it’s a problem.”

Student C fought for two years to get a diagnosis. After being ignored by all of the people she was referred to by the counseling center, she “got diagnosed within a month” of reaching out to someone her sister’s therapist referred her to. She described a great experience meeting the doctor, and after being diagnosed at the first meeting stated that she

started “crying, not from sadness, but from overwhelming joy and just relief that, like I don't have to keep getting so close to getting a diagnosis, and then having to restart. ... And now, just being able to live as an autistic person, be able to have that label for myself, and just feel. I guess, reassured in my identity. It really improved my mental health.” From there she felt relieved to be able to get more accommodations such as limited attendance, and to “... get the resources I need, and be able to have a voice for myself.”

In an essay in *Aquamarine Blue 5*, Darius, an autistic European university student describes having “... extremely good memory and concentration for things that interested me but none at all for things I found pointless (Darius, 2002, p. 10).” From his story and others, I gleaned that a principal cause of struggle for autistic college students is that they have, as Darius described himself as having, a “mosaic pattern of skills and deficits” (Darius, 2002, p. 14). In other words, the struggles of no two autistic people are exactly the same. Autistic people may struggle with things non-autistic people do easily, and autistic people may do things easily that non-autistic people find difficult. Interventions starting at a young age assume a universal idea of what tasks and skills are, as Darius described “simple” and “difficult” when those ideas are not universally applicable to neurodivergent students (Darius, 2002, p. 15). These atypical patterns of skills and deficits may make it hard for autistic people to be believed when they speak about their struggles.

Another difficulty can come when one has learned to mask so well that others may not consider the possibility that they are autistic. As previously mentioned, Student C reported that during the time she sought a diagnosis, “felt kind of insecure, thinking that I might be autistic.” Having a diagnosis early gives one critical self-understanding, rather than

resenting one's traits. Getting a diagnosis helped Student C grow to "... understand the things about me that I grew to resent and be able to accept them." Additionally, as Cage & Howes, (2020) showed, difficulty accessing a diagnosis can factor into students considering if they want to continue in college at all, with potential that they may drop out. Receiving a diagnosis early can be critical in helping autistic people know and advocate for themselves, gain understanding from family, teachers, and peers, continue their studies and get the accommodations they need to succeed.

Masking and Unmasking

Although in many ways I have felt accepted as an autistic person in college, I have wondered to what extent I am myself versus how much I am masking. Have I truly learned to be myself, and people are accepting of that, or have I merely learned to put on an acceptable facade. As Student B described, people in college can be more accepting because people have matured, and are generally more accepting of difference. Despite this, making meaningful connections in a new environment can present challenges (Irvine & MacLeod, 2022). Student C also discussed this matter saying that a benefit of living in an apartment by herself was getting to "unmask fully".

Learning to be comfortable in one's own skin involves learning to notice one's own behavior and ensure that they are comfortable with it. Healthy social relationships are reciprocal, meaning that autistic people should not be expected to regularly compromise for their non-autistic friends' comfort if said non-autistic friends are unwilling to meet their autistic friends halfway on anything. In a world where people, as Student C described, are taught by society to resent themselves for their natural behaviors, encouraging unmasking is

of the utmost importance.

Acceptance

Having accepting friends has been vital to my sense of belonging. It surrounded me with similarly academically minded peers, which I did not have many of before, who were in a program that was naturally more accepting of difference. I met people I did not feel like I had to mask around, and who were happy to have me with them. They also did not seem to be judgemental when I stimmed a little when I got really excited about something, which I would have been a bit wary of doing around my friends previously. As other autistic students have reported (Bailey, et al., 2019), this social connectedness has greatly contributed to my emotional well-being. I felt like I was truly being myself rather than, as Student C described, “watching what other people did, and then learning how I can do that to seem like I’m like them”. My family has continued to support me throughout this time, though mostly as people to talk to since I graduated high school, and my friends have always been available to talk to when I needed them most. Feeling supported and validated has helped me maintain involvement in student groups and organizations, bolstering my connections and building new ones. These factors have been cited as connected to well-being by autistic students (Bailey et al., 2019).

While I do believe many of my challenges come from a lack of understanding and acceptance, there are some challenges that I face being autistic that would not be resolved by society simply being more accepting. For example, having limited social battery, may mean that even when I would otherwise want to go out with my friends, I may need to stay home just to sensorily recharge. I would also still struggle at times with sleep. I sometimes have

difficulties finding time in the day, after I have decompressed to get work done. As a result, I have on occasion had to stay up late to do work and get up early to go to class or work. It also means that I must consider how much I would have to mask, and stay in potentially sensorily overwhelming environments and situations when looking for jobs. However, I believe these challenges are just as connected to my autism as the things I have previously mentioned as essential aspects of who I am. This is why I choose to identify as an autistic person, as opposed to a person with autism.

Embracing Autistic Identity

Another factor in my experience that allowed me to embrace my identity as an autistic person as opposed to a person with autism was having a safe space to reflect on my identity. Living away from my parents and having the freedom to mold my experience and form my own identity, I began to realize how much being autistic shaped the way I lived my life in many not necessarily negative ways. I saw how much more I enjoyed small gatherings with a few close friends over events where I was with a lot of people I did not know. I began to notice how much joy my special interests brought me, and the happiness that came from having someone I could talk to who shared that interest. I realized that my natural ability to immerse myself in things I am interested in whether they be academic or recreational was something that made me who I am. Being able to feel overwhelming joy, and being unafraid to express it, experiencing pure sensory bliss when listening to music, these were all things that I came to see as connected to my autism. From this reflection, I concluded that being autistic made things challenging for me. However, I realized that much of the problem came from living in a neurotypical-normative world as a neurodivergent person. In this world, the

differences in the way I expressed myself and experienced happiness were seen as deficiencies that needed to be corrected rather than valid alternative means of communication and experiencing happiness.

It's a Choice to Identify as Autistic or Not

The shift in my identity from a person with autism to an autistic person represents more than semantic convenience. It marks a shift in my perspective of autism from a challenge that I overcame to something that is intimately connected to my gifts and struggles. Students A and B did not indicate any preference, however Student C indicated a preference to be identified as an autistic person. Although the difference between being referred to as having autism and as an autistic person is vast for me and others, it is important to acknowledge that not all autistic people feel this way. To some, autism may seem an external condition, and they would prefer to be referred to as people who have it. It is important for those outside of and within the neurodivergent community to recognize that individuals know themselves best and to respect an individual's preferences even if it goes against professional advice or the preferences of other neurodivergent people.

Variability of Support and Resources in College

In addition to my experience with supportive friends and family, the Office of Disability Resources (ODR) has been a helpful resource for me in adjusting to college life. Within the realm of any struggles I could have anticipated, ODR has been able and willing to get me the accommodations I needed, such as single housing, extended time, and a distraction reduced environment for exams. Single housing has been particularly vital, as it has given me a space to decompress and take the time I need to recuperate to enjoy a social

life and perform at my full capacity academically. I also experienced anxiety about my classes and workloads, having concerns about completing my classwork on time while still maintaining a social life. The Counseling Center was helpful for me in getting through that, and referring me to an outside therapist when I needed to talk more frequently. Experiences with disability and other resources can have a dramatic impact on an autistic student's college experience.

The positive experience I have had with ODR is not representative of all however. Autistic students have reported not having a particularly active support system in colleges (Irvine & MacLeod, 2022). Student C described the university as not being particularly helpful in their pursuit of a diagnosis. They reported having a bad experience trying to access care in the community and struggling with a lack of understanding and respect of boundaries from ODR. According to Student C, ODR dismissed their reported needs, as she described, "... giving me a bunch of examples of why things wouldn't work, and then, when I would try to speak they would speak over me, and then they asked what a meltdown looked like for me, which I thought was really inappropriate. ... I don't think I should have to go into depth about what it looks like for me to be taken seriously." Their struggles were less after receiving a diagnosis, but the process was made far more difficult by ODR. Other students, such as those in Cage & Howes, (2020) reported faculty and staff only doing the minimum for them, as well as only being able to provide academic accommodations when their needs were primarily within social and emotional realms.

Reaching out to the Office of Disability Resources, having supportive family, counselors, and friends helped me get the help I needed in college. Having systemic and

individual support was something I saw as a key factor. Student B reported being able to receive accommodations from ODR, and their proactivity once they reached out as important. I have also generally had very supportive professors, willing to go beyond the required accommodations if I had expressed a need. Student B has reported similar experiences with their professors. This individualized support, particularly in the academic realm, was a factor in success highlighted in Irvine & MacLeod (2022), particularly in Bailey et al. (2019) and Gurbuz et al. (2019).

Not all students find this support at the university however, and the resources they have in place to help can also be harmful. Student C struggled to find support within the system while pursuing a diagnosis, being told by counselors to “stop the self diagnosis” and being asked inappropriate and invasive questions by ODR. Additionally, I struggled to find support when I was facing disability related struggles in my program of study. Furthermore, many of the resources the counseling center pointed Student C to did not respond back, and the counseling center was unaware of the place they got their diagnosis. It is also difficult for students when they do not have an awareness they might be autistic in college (Cage & Howes, 2020). These varied experiences show that many individuals in the system care and want to help autistic students, but many are still not well informed, and this problem needs to be addressed.

Students A and B however, perceived ODR as a beneficial resource. Although occasionally Student A’s professors did not check modules or ask if anyone had accommodations, their experience with instructors was overall positive. Student B described ODR as having a beneficial “streamlined” process as well as having an experience of very

helpful and understanding professors. My story and these appear to indicate, as Student B observed, “Almost every person I've met that isn't just outright a terrible person has been really helpful, really trying to benefit and really trying to be kind which is amazing. It just as you know, as a unit, it doesn't feel like they try the hardest.” However, on some level autistic issues are only addressed on the systemic level as much as is necessary to comply with the law and be deemed as Student B stated, “politically correct”. It shows that individuals within the system may care, but not all those operating it have the knowledge to best help autistic people. I also noticed that as I tried to work through unanticipated difficulties, individuals wanted to help me, but the hands of the system were tied. Without resources faculty and staff may have little understanding of autism, as was reported as an obstacle in Accardo et al. (2019), which can lead to misplaced or even harmful approaches even though they may be well meaning.

Similarly, Steven Kapp, in his chapter *Higher Education Transitions* (Kapp, 2012) in *Navigating College: A Handbook Written for Autistic Students From Autistic Adults*, highlights that proactive rather than reactive communication of needs and maintaining robust academic and social support networks are essential to success. Furthermore, Zoe Gross' chapter *Better Living Through Prosthetic Brain Parts*, the handbook emphasized it is vital to be able to hold oneself accountable, and it may be necessary to adopt coping strategies to which one may not be adjusted (Gross, 2012).

Having Supportive Friends.

Having supportive friends is another vital component to success in college. Being in the Honors College and Appalachian Community of Education Scholars (ACES) program

gave me structured opportunities to meet and form relationships with similarly minded students, who were accepting of me as I was, not for my mask. I have also gotten involved with other groups on campus such as Film Club, the Geek Guild, and the Neurodivergent Students and Allies Club (a club which I and a couple of other neurodivergent students founded in the Fall of 2022 as a place for neurodivergent students to feel safe to be themselves, and, talk about issues pertaining to neurodiversity). Having this natural support group also greatly improved my emotional well-being. Student B attributed their improved relationships with instructors and peers to generally being around more mature students and people who are more accepting of difference. These may have also been factors in my experience. Meeting other autistic people and forming relationships was a factor that Student C reported as contributing to their emotional well-being.

Throughout *Aquamarine Blue 5* (Prince-Hughes, 2002) many of the individuals did not discuss academics as a primary challenging area for them in college. It was not academics, but rather the social arena that he and other autistic students stressed as being problematic. Although this is not explicitly explained, perhaps it might be because the academic world can have greater structure and a simpler set of rules to follow for success. The structure of the social arena can vary by situation, and does not come with as much a set of rules. The individuals contributing to the collection of essays discussed feelings of social isolation, giving in more than they were getting out of relationships, and struggling to empathize with friends who seemed to always be more busy than themselves.

Social and emotional well-being are vital for all college students. Grades, however, should not be used as a means of measuring social and emotional well-being. Keeping up my

grades was not a struggle for me, but establishing social connections was a tremendous effort. Student C's grades also masked their needs to ODR, as she described, "I feel like they were trying to tell me that because I do well in school, and I'm able to succeed, that means I shouldn't have accommodations." It cannot be taken for granted that academic success indicates social and emotional well-being. In Cage & Howes, (2020), mental health was a major factor cited for autistic students as to why they did not finish their program. Therefore, addressing these needs is vital to supporting autistic students throughout college.

Self Advocacy

Something important which is found latently throughout my autoethnography that I feel needs to be addressed is self advocacy. I have advocated for myself in going through the accommodation process and communicating my needs with my instructors and people in my life. Student C's pursuit of a diagnosis was a particularly powerful process of self advocacy as a way to say, "You guys can quit bugging me about this, because I know myself better than you all know me, and I think it's unfair that people tell me I'm not autistic." She took a major step in "wanting to unmask and be able to understand myself and have the terminology to describe my entire life experience." It is important for autistic people to proactively advocate for their needs and demand acknowledgement where they are not receiving it.

I consider the work of reflecting on my experience and examining those of others in part an act of self-advocacy. I chose this topic out of any that I could have selected because it gave me the most opportunity to learn about myself. I have emerged more knowledgeable of myself and my place within the autistic community. It has given me a clearer sense of who I

am, and how I can live as my authentic self.

Discussion

Disability resources can be an invaluable support for autistic college students, however, they are not perfect. Even if they are delivered by well informed and willing individuals, the system lacks full integration (Irvine & MacLeod, 2022). Faculty and staff are also inconsistently informed, and may not always be aware of resources in the community (Nachman, 2022). Professors may also have little information on autism and the needs of autistic students, but with appropriate training, they can create more inclusive classrooms (Nachman, 2022). To better support autistic students, systems need to be robust, and faculty and staff need to be consistently informed and better connected with local resources. Additionally, support should be offered proactively and students' needs assessed regularly rather than reactively in response to crises.

While personal experience is a valuable tool for unique cultural, social, and political insights, autoethnography is most powerful when put into conversation with literature and the experiences of others (Adams et al., 2017). Literature in recent years has demonstrated that autistic students face many challenges in university life, and that autistic traits can also benefit students in that setting; however, it also illuminates a scarcity and inconsistency in research of the autistic higher education experience. Many of my experiences and those of the students I interviewed were also reflected in a recent metasynthesis of studies of autistic college students (Irvine and MacLeod, 2022), as illustrated throughout the results section.

Suggestions for Supporting Autistic College Students

Based on the information my experience, and those documented in the studies and

anthologies I have read, and surveys and interviews I conducted I have three major suggestions for supporting autistic college students:

- 1) Offer a neurodivergent Residential Learning Community
- 2) Provide single rooms in residential housing.
- 3) Have a place to go to decompress on campus.

Offer a Neurodivergent Residential Learning Community

One idea for support of autistic students, which I synthesized from Student C's proposal and my own experience, was a Neurodivergent Residential Learning Community. Student C proposed more spacious rooms and pairing neurodivergent students together. This idea of putting more neurodivergent students together segwayed into an idea for a community of neurodivergent learners who could have shared living as well as personal and professional experiences, as the communities I was in were vital to my development of networks and experiences.

The Appalachian Community of Education Scholars (ACES) is a four-year teacher preparation program which I am in. As part of that program, I lived in the same dorms as my cohort for the first two years, and throughout I was able to bond with similarly minded and professionally directed peers through shared community-building and professional development experiences around education. Additionally, there was a peer mentorship element, which Ames et al., (2015), Gillespie-Lynch et al., (2017), Thompson et al., (2020), and Roberts & Birmingham, (2017) showed to have potential for autistic students. Having these opportunities to bond with a smaller group of people helped me build a social support network and learn self-advocacy as it gave me opportunities to make professional

connections. Events allowed me to participate in a culture of self-directed learning while also having structured opportunities which can be beneficial for autistic students who may struggle with initiating social activities as cited in Cage & Howes, (2020). I am also in the Honors College, which has the benefit of offering smaller and more discussion oriented classes, as well as connection with like-minded peers.

A program like ACES with community-building events and activities and self-advocacy focused professional development experiences for neurodivergent students could be vitally conducive to their success. Connection with a cohort of like-minded students, and possibly a peer mentor who has had similar experiences can be a vital source of community and validation. Additionally, events and activities can facilitate bonds and give more structure to students' schedules. Curriculum focused on self-advocacy also centers around the priorities of autistic students, and helps them navigate the bureaucracy that is often a great challenge.

The presence of such a group on campus would allow more opportunities for students to organize, and provide motivation for resource providers to keep their resources up to date. College can be stressful to navigate with autism, and such a community would give autistic people a place to support each other. Ames et al. (2015), Gillespie-Lynch et al. (2017), Thompson et al. (2017) and Roberts et al. (2017) demonstrated peer mentorship could be an effective intervention for autistic college students, and I feel that it was effective for me to navigate the ropes in ACES. While above-cited studies demonstrated effectiveness with neurotypical mentor-autistic mentee pairs, it may be beneficial for autistic students to have autistic mentors who can relate to them from personal experience. The peer mentorship

programs analyzed also did not follow students throughout their careers, however, adjusting initially to college is not the end of a journey. As autism is not something that can or should be eliminated it may be wise to look into programs that follow students throughout their college tracks.

After their diagnosis, Student C found connecting with other autistic students vital to their growth in their identity. After years of not understanding oneself and loathing their autistic traits, they came to find community in other people. Although I entered college in a much different place, connecting with other autistic people has helped me realize how much of who I am and where I am now is because rather than in spite of me being autistic. With my identity secured, making connections was relatively easy for me, but without that security it may have been much more difficult, particularly if I did not have a diagnosis. An RLC for neurodivergent students could be exactly what autistic people discovering themselves for the first time need to self-actualize and develop self-advocacy and resilience. It could serve as a space for them to experience their unfolding of the self, and receive the support they need to succeed.

Provide Single Rooms in Residential Housing

Being able to make a space one's own is also particularly important to autistic students (Grabsch et al., 2021). Single housing is one way that this need could be provided. Housing is an area of college life that autistic students struggle with. Student B reported having no place to go for sensory relief on campus, stating that, "when I get overwhelmed, especially with light, there is literally nowhere on campus I can go because every hallway, all the locks, everything has street lights, headlights, lamps, every single thing, there's literally

not one place I can go”. They reported that they would often, “go to the bathroom, turn off all the lights, put on an eye mask and sit there in the shower, hoping to feel better”. These sensory issues also led to roommate and dorm living problems as Student B describes, “My roommate uses that thing to make ramen, and it makes me want to die smelling the cleaning products, hearing little things throughout the day in the dorm building that my friends can’t hear.” Student C reported similar issues with executive functioning being impacted “when something isn’t clean, or someone else is in there, and I never have time alone.” She also states that living alone off campus has been a benefit because of, “... the time alone mainly, and being able to decorate and clean my space how I would, I like my time alone and private spaces have always been really important to me.” Additionally, ‘peace and quiet’ was cited as a necessity for success (Irvine & MacLeod, 2022 p. 54). Having had a single room, I can attest to the benefits of having this ‘peace and quiet’ and the benefits of having a guaranteed space to be away from people and find sensory relief. Without a roommate I did not have to worry about working out things or compromise on my space, and my room could be my space for sensory relief. Many are not so fortunate, and Students B and C reported, living with a roommate was difficult. Student C reported doing much better having an apartment without a roommate this year.

Have a Place to go to Decompress on Campus

Student B proposed in the survey, “a sensory deprivation room that’s open 24/7. It could be as simple as a quiet zone with little cubicles and very dim lighting for people with autism to use.” As they elaborated in the interview, it could also have a backroom where services and resources could be provided for autistic students in the same way the Women’s

Center and LGBT Center provide resources. Student B also proposed the idea of more sensory-friendly rooms for autistic students. These could be rooms with different walls to catch sound, rooms away from direct sunlight, or with more autism-friendly lighting.

Having one's own space and time to decompress are essential for autistic success. Daily life is significantly more difficult for autistic people because of sensory issues, and not having a place to find relief. A place to provide sensory relief open 24/7 on campus could make a world of difference. Autistic students have cited libraries as places where they can enjoy breaks, however, they have reported a need for a completely private space such as a "study cubicle" to feel they truly have privacy (Anderson, 2018, p. 650). Student B described a place on campus that would be dimly lit and soundproofed that students could come into to decompress at any time. There could also be resources such as information about ODR programs and resources, flyers for disability-related groups on campus among others available in this space for students to take as they come or go. Ultimately, colleges need to provide more housing accommodation and places for sensory relief for autistic students.

Limitations

As with any research there are limitations, limitations for this study include a small number of responses and interviews from my own research, the variability of the autistic experience, and my personal blindspots because of early diagnosis and support.

Potential for Different Insights from a Larger Scale Study

A limitation to this study's generalizability is the relatively small number of survey responses and interviews from my own research, as well as the fact that all respondents were Appalachian State students. A larger sample of survey respondents and interviewees from my

own research may have uncovered more insights or further elaborated on those I uncovered. Reaching out to students beyond Appalachian State may have also born more generalizable results. Nevertheless, this particular study was an autoethnography focused on helping me to better understand my own autistic college experience. Seeking out the experiences of other autistic college students (through published accounts and several surveys and interviews with fellow Appalachian State students) has helped broaden my self-understanding and gain deeper insights into the nuances of the college experience for other autistic students.

Autism is a Spectrum

During my conversations with fellow autistic college students, I began to truly understand that my experience is not reflective of any universal autistic experience because there is not one. Every autistic person's experience is different, as is the nature and scope of their support needs. I am one person, the students I surveyed and interviewed are individuals, and the participants in the studies and contributors to the books I reviewed are individuals. Any adequate support system for autistic college students will need to acknowledge the diversity of support needs among students. Recognizing this diversity among autistic students, these systems will need to flexibly develop creative and individualized plans tailored to each student's unique needs, skill sets, and strengths.

My Blind Spots Because of Early Diagnosis and Support

I was diagnosed and received positive support during my childhood which is contrary to the experience of many others. Because of this, I entered college with a robust support network of family, doctors, and vocational professionals; I was able to anticipate my needs, get the proper documents to ODR in a timely manner, and receive the academic and

residential accommodations I needed. Because of this autoethnographic research project, I have had to learn to not take the impact of early diagnosis and accommodation for granted.

The validation to oneself and others and the pathway to accommodations that a medical diagnosis and a good, knowledgeable doctor provide are not things I have had to think about. However, they can mean the world to individuals who have been treated as broken normal people who need to be fixed and not acknowledged as people who are simply different and need understanding and accommodation. Having a room to myself, I have always had a place I knew I could have time to myself and for sensory recharge. However, this is not an accommodation all autistic students are able to obtain, and there is not a place on campus that autistic people can always go to for sensory relief. Additionally, having support I was taught to advocate for myself, and develop my executive functioning skills from a young age. This is also not universal, and coming into college without these skills can make it a much more difficult experience.

Conclusion

Just as it is for non-autistic people, college is a critical turning point in autistic students' lives. It is a unique time and place for reflection and self-discovery. In some ways, it can play to the strengths of autistic people in providing them an opportunity to dive deep into their special interests and learn to channel their passions into a sustainable career. In others, it puts them at a disadvantage with small dorm rooms designed to be shared, the inconsistency in class schedules and campus activities, the pressure to always be socially active, and the navigation of relationships with peers, faculty, and instructors. In these formative years, the availability and quality of support can change the course of a person's

life, especially for those already vulnerable. There needs to be a change in college culture away from measuring success by academic performance alone, and toward more holistic measures.

Through exploration of myself and reflection upon my experience while seeking out the experiences of others, I have learned a lot about what it means to be autistic and what autistic people need. Autistic people have many unmet needs in this world, particularly in the institution of higher education. I have experienced both the great potential of understanding individuals and the catastrophic failures of systems, and have learned from others who have as well.

As I began to see myself more in these stories, I began to see autism more as a part of me. I also began to realize that for the largest portion of my life, I may have been directed away from my true self, as I was taught to mask and make myself appear more neurotypical. I am grateful that I was able to do well in school, make friends, and have so many opportunities, and I would not exchange the opportunities I had for anything. I am also grateful for the skills I learned in studying, independent learning, and social interactions that helped me in college. However, I feel fortunate that I have been able to rediscover, and for a change, proudly proclaim my autistic identity. I have told all of my friends that I am autistic, and I feel safe to be my authentic self around them. This is something I would not have felt with any of my friends before embarking on this research.

This research experience has shown me the power of autoethnography to allow the researcher to understand experiences simultaneously within and outside of their own. Autoethnography allows autistic people to write back to cultural scripts which depict them as

unfeeling, uninterested in relationships with others, and unable to function in and contribute to non-autistic society. Autoethnography can also help autistic people to uncover how their other identities may marginalize or privilege them within the autistic community.

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Appendix

Survey Questions:

1. Do you identify yourself, or prefer to be identified as a person with autism or an autistic person?
2. When were you diagnosed with autism?
3. Did you feel accepted as an autistic person at home and/or in your community prior to college? Why or why not? You may answer in as much detail as you are comfortable with.
4. What is your experience at university like? What supports are most helpful to you? What could the university do to better support you? Please describe as much as you would like, your perception of the accessibility of the university (in terms of physical accessibility as well as obtaining reasonable academic and housing accommodations), your relationships with professors, advisors, and other faculty, your relationships with your peers, and anything else you feel is important to know. Also, please describe any additional efforts you believe the university could put forth to better support autistic students. You may answer in as much detail as you are comfortable with.
5. Is there anything you would like to share about yourself or your experiences that was not addressed in the previous questions?
6. Would you like to participate in a follow-up interview over Zoom? This will be no longer than one hour, and you will be asked clarifying questions about your responses to this survey. If you would like to participate, you should receive an email

from reepme@appstate.edu asking about your availability for the purpose of scheduling the meeting.

If you are experiencing significant distress about any information shared in this form, you may contact the Appalachian State Counseling Center at (828)-262-3180.