



Examining the Neurodiverse Postsecondary Experience

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ABSTRACT

The aim of this investigation was to examine the lived experience of postsecondary students who identify as neurodiverse. Participants included four females and one male, ages 20-23 years, matriculating in their second to fifth year of postsecondary education. The investigation followed a phenomenological research design, with data collected through face-to-face interviews. Participants were asked to describe their educational experiences including perspectives on accommodation use, interactions with faculty and peers, and management of day-to-day activities and academic demands. Analysis of interview data resulted in the emergence of three contextually relevant themes: (a) Accommodation Pros and Cons, (b) Perceived Flaws in the System, and (c) Necessity is the Mother of Invention. The emergent themes represent positive and negative experiences and highlight participant ingenuity and determination navigating the postsecondary environment. Findings corroborate earlier studies and suggest further examination of neurodiversity awareness, disability-related stigma and bias, and the effectiveness of disability supports and services provided in the postsecondary environment.

Keywords: neurodiverse, postsecondary, accommodations, stigma, stress, lived experience

INTRODUCTION

Attending college or university is often described as an exciting, challenging, or life-altering experience; A time to meet new people, explore new places and opportunities, and to grow academically and personally (Hassel & Ridout, 2018). The life of a college student is also commonly identified as stressful: academically, financially, socially, and emotionally (Pitt, Oprescu, Tapia, & Gray, 2018). For students with Autism Spectrum Disorder (ASD) and other neurodivergent conditions (i.e. Attention Deficit/Hyperactivity Disorder, Tourette syndrome, dyslexia, dyscalculia, dysgraphia, dyspraxia, hyperlexia), these stressors may be compounded by a variety of additional challenges: managing (a) day-to-day activities, (b) changes in routine and time demands, (c) social demands, (d) sensory demands, (e) decisions regarding self-disclosure and self-advocacy, and (f) experiences related to disability-related bias or social stigma (Cole, & Cawthon, 2015; Daly-Cano, Vaccaro, & Newman, 2015; Longtin, 2014; McGregor, Langenfeld, Van Horne, Oleson, Anson, & Jacobson, 2016; Roux et al., 2015; Shmulsky, Gobbo, & Donahue, 2015; Van Hees, Moyson, & Roeyers, 2015).

While Title II of the Americans with Disabilities Act (ADA) (1990) and Section 504 of the Rehabilitation Act (1973) mandate a variety of academic and accessibility supports for qualifying postsecondary students, the process of obtaining and implementing said supports drastically differs from the K-12 service model to which students are accustomed (Mulder & Cashin, 2014). Primary and secondary supports are defined by a comprehensive, collaborative service model, driven by the student's Individualized Education Program (IEP) (United States Department of Education, 2000) or section 504 of the Rehabilitation Act of 1973. The IEP is created, developed, and directed by educators, parents, related service providers, and educational administrators. The recipient student is considered a member of the team, but concerns, decisions, and related discussions are typically initiated and orchestrated by educators and parents.

In contrast, the postsecondary disability service model is student-driven, where the onus of seeking and employing supports falls squarely on the recipient student's shoulders (Mulder & Cashin, 2014; Roux et al. 2015). Self-disclosure is a necessary first-step without which students do not acquire necessary supports (Daly-Cano et al., 2015; Longtin, 2014). Unfortunately, many students choose not to disclose for a variety of reasons: (a) a lack of knowledge about disability services and available accommodations, (b) misperceptions about one's disability and related needs within the postsecondary environment, (c) the belief that specific accommodations would not be needed, helpful, or may be

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detrimental, and (d) avoidance of negative stigma related to the use of accommodations (Cole & Cawthon, 2015; Roux et al., 2015). The practice of non-disclosure, or attempting to conceal one's disability related challenges, typically leads to heightened stress and anxiety levels (Van Hees, Moyson, & Roeyers, 2015), and consequently, lower rates of overall satisfaction with the postsecondary experience as compared to non-disabled peers (McGregor, Langenfeld, Van Horne, Oleson, Anson, & Jacobson, 2016).

It is clear, although well-meaning, the current postsecondary disability service model may be less than optimal to meet the needs of many students. Indeed, Shmulsky et al. (2015) suggest, in addition to mandated services, there is a need for colleges to develop transition programs tailored to the unique needs of students with ASD. Ideally, such programs foster collaborative partnerships with parents, provide early, small-group orientation for students and families, and incorporate trained advisors to maximize student success (Shmulsky et al., 2015). The need for strong self-advocacy skills has also been identified as critically important (Cole & Cawthon, 2015; Daly-Cano et al., 2015; Kragland-Gauthier, Young, & Kell, 2014), as well as the provision of professional supports for faculty (Burstahler & Russo-Gleicher, 2015).

According to Gelbar, Smith, and Reichow (2014), there is a "scarcity of research concerning the experiences of college students with ASD" (p. 2599), as well as the broader population of students with non-visible, specific learning disabilities (SLD) (Cole & Cawthon, 2015; Daly-Cano, Vaccaro, & Newman, 2015). Burstahler and Russo-Gleicher (2015) concur, stating "more research needs to be done to further identify obstacles and solutions to successful college course completion for students with disabilities" (p. 207).

Therefore, the goal of this investigation was to examine the lived experience of students who self-identify as neurodiverse; to report their perception of the postsecondary environment, including perceived barriers and supports to academic success. For the purpose of this study, Houting's (2019) description of the term neurodiverse was used to define the population of interest: Individuals who possess learning and processing differences considered "both a natural variation [of the human genome] and a disability" (p. 272). This dual classification promotes an attitude of respect and acceptance for the uniqueness and capability of the individual, while also emphasizing the need for appropriate supports and services (Houting, 2019).

METHODOLOGY

This investigation followed a phenomenological research design, obtaining data through the interview process. Following approval by the targeted university's Institutional Review Board (IRB), participants were recruited via email notification sent by the Disability Services Coordinator. The recruitment email contained a detailed description of the study and informed consent. Interested candidates voluntarily contacted the primary investigator via email, and an interview time and location was

scheduled at the participant's convenience. All participants provided signed informed consent, self-identified as neurodiverse, were registered with the university's disability support service, were over the age of 18 years, spoke English as their primary language, and were (at the time of interview) full-time undergraduate, and in one case, graduate postsecondary students.

Interviews followed a semi-structured interview guide, were audio-recorded, and conducted face-to-face. Participants were asked to describe their educational experiences including perspectives on accommodation use, interactions with faculty and peers, and management of day-to-day activities as well as academic demands. Interviews varied from 1.5 to 3 hours in duration, during which time participants' spoke freely and at length about their individual experiences. All interviews were conducted by the primary investigator and transcribed verbatim.

Data analysis followed Hycner's (1985) systematic guidelines for phenomenological analysis of interview data including: (a) transcription, (b) bracketing and phenomenological reduction, (c) listening for a sense of the whole, (d) delineating units of general meaning, and (e) units of relevant meaning, (f) eliminating redundancies, (g) clustering units of relevant meaning, (h) determining themes, (i) contextualization of themes, and (j) creation of a composite summary. Transcriptions were examined individually and then collectively in order to construct a composite summary reflective of the participants' perspectives as a whole (Hycner, 1985). Member-checking was employed to increase trustworthiness and ensure credibility of analysis.

RESULTS

Participants included five individuals, one male and four females, between the ages of 20 and 23 years, matriculating in their second to fifth year of education. Two participants were transfer students, having completed at least one academic year at another four-year institution, and one individual completed coursework at a community college while a senior in high school. Therefore, while all participants were enrolled at the same institution at the time of interview, data reflects experiences from four institutions of higher education. All participants self-identified as neurodiverse, disclosing one or more of the following diagnoses: Autism Spectrum Disorder (ASD), Attention Deficit Hyperactivity Disorder (ADHD), dyslexia, dysgraphia, auditory processing disorder, and non-specific learning disability.

Following interview transcription, subsequent phenomenological reduction, and delineation of units of meaning, 10 clusters of relevant meaning were identified as common across all participant data: (a) Difficulties regarding disclosure and obtaining or requesting supports, (b) Disability-related impact on the learning process, (c) Perceived benefits and barriers to accommodation use, (d) Family supports, (e) Perspectives of instructor interactions, (f) Perspectives of peer interactions and social demands, (g) Demands of versus secondary education, (h) Managing day-to-day activities, (i)

Self-care, self-help, and self-preservation, and (j) Learning from past experience. Final synthesis of clusters of relevant meaning resulted in three contextualized emergent themes: (a) Accommodation Pros and Cons, (b) Perceived Flaws in the System, and (c) Necessity is the Mother of Invention.

Accommodation Pros and Cons

Each participant identified approximately six to eight academic accommodations for which they qualified, reporting both positive and negative experiences related to implementation. Reported accommodations included the following: (a) abbreviated assignments, (b) use of audio books, (c) excused from using Scantron™ score sheets for testing, (d) extended time to complete assignments, (e) extended time for testing, (f) provision of note-taker/note-sharing, (g) option to take tests orally, (h) preferential/priority seating in the classroom, (i) quiet environment for testing, (j) provision of a reader for exam questions, (k) use of recording device during lecture and lab sessions, (l) supplemental instructions or notes from instructor, and (m) allowance of computer for note-taking in the classroom.

All five participants reported use of a quiet testing environment and extended time for testing as beneficial. In addition to diminishing distractibility, and providing adequate time for individuals with slower reading and processing rates, these accommodations were clearly viewed as stress relieving. As Participant 3 (P3) states,

“Extra time on tests is...helpful, I mean sometimes I don't necessarily use it, but it's nice knowing that it's there so that I don't feel stressed out” (P3 Transcript, lines 145-147).

Stress relief was also the clear benefit expressed by Participant 2, stating

I have extended time [for testing]. That is really helpful... I really, really think I should get it on like certain assignments because that, that's a really big stressor for me. Like to the point where like I get physically sick. I have um, I take it [exams] in the testing room. Which that's really helpful cause like, when everyone else has to take it in like the big, big auditorium like, my [diagnosis], like I can't. I'm like there is way too many people in here (P2 Transcript, lines 187-192).

However, while extended time for testing and testing in a quiet environment were described as stress relievers, both were also perceived as problematic. Expressing annoyance with the logistics of scheduling extended test time, Participant 1 (P1) shared the following about a course that included quizzes at the start of each class:

I had to go to class at 7:45 [a.m.], sit there, wait for them [the other students] to like be done with it [the quiz]. ...So I would just sit there, they would be taking it, and then she [the course instructor] would lecture after...and then I had a class right after that. So, I would take it [the daily quiz] at 11:30 a.m., after she [the course instructor] already taught new information, when everybody else got to do it like before she

taught the new information. So, like that was kind of annoying (P2, Transcript lines 392-402).

In addition, testing in a location other than the student's typical classroom was perceived as stigmatizing, as Participant 3 (P3) states,

I don't personally like having to go to another room to take a test 'cause I feel like other students notice and it's just like, I don't want to stand out. ...I guess like going, doing it in another room um, it's not helpful cause, I guess it just like, I feel stigmatized. I don't know what other word really to use. ...I don't want, I feel like you don't want to be like different (P3 Transcript lines 137-165).

This sentiment was echoed by Participant 1 (P1), stating

I'm sure they [peers] pick up like I'm not there when they take the tests normally. ...But like, I don't need everyone knowing. Like, I'm the same as you [peers considered neurotypical] but I just need a little something extra. Like, you [peers] don't need to know everything (P1 Transcript, lines 417-419).

Feasibility and stigma were also fundamental concerns regarding the use of extended time for completion of assignments. As P1 stated,

I don't really use the extension on assignments. ...like with group work ...I can't get an extension on it because then like my entire group would need an extension. And like, that's not fair to everyone else. Like it's, [mimicking another student] oh then, I want to be in [student name] group. And like, I don't want to be in your group (P1 Transcript, lines 333-351).

In addition to extended time for testing and a quiet testing environment, note-sharing was also identified as one of the most helpful, but problematic accommodations. As P2 stated, *“I rely heavily on the note-sharing program, which I really like. So, like that's been really beneficial for me”* (P2 Transcript, lines 214-215). However, later in the interview, P2 shared the following,

So, depending on the person who does the, who's like writing it [the notes], sometimes they don't put down all the information, sometimes they don't write at all. Sometimes they don't post the notes until like the day before the test. So, that has been like a frustration.” (P2 Transcript, lines 500-503).

Note-sharing was also described as having the potential to be helpful, but was not currently employed by Participant 4 (P4), citing the following reasons:

I try to do everything on my own. The reason I didn't do it this year [use a note-taker] is I think it's very easy to get lazy that way, and to not pay attention in class, and to not take your own notes, and to not try if someone's just giving you the notes. But I think next year when things move faster [moving into core courses] ...that it might be helpful (P4 Transcript, lines 113-117).

The accommodation of using a recording device was similarly viewed in both a positive and negative light, as comments from P2, P3, and P4 illustrate:

That's what I do before bed. I will listen to recordings from my classes that day. So like, that's how I fall asleep. I listen to recordings from my classes (P2 Transcript, lines 195-197)

I wish I would've had the audio-recording thing sooner. I have listened to those like, just driving, like while driving in the car, ... and it does help ... Like if I listen to them more than once, it's even like, I mean I don't have the visual but it does help if I hear them like more than once (P3 Transcript, lines 141-144).

I can [audio record lectures], but there's issues that run into play ... it's just very annoying to listen to it again, and you know, I probably have to listen to it, you know, another once or twice, which is very annoying, and, it's also time consuming, and I have a life, and I need down time, and I don't want to be taking notes all day every day. And it's pausing and rewinding and, so even, you know it's an hour and a half class, you're talking double that time to just get the notes from it. ... I think it has the potential to be useful if you have oodles and oodles of time, but I don't (P4 Transcript, lines 136-186).

In addition to requiring a great deal of time, use of a recording device was also described as a technological challenge and additional stressor by P1, stating

I do have a recorder, but I'm not really good at using it. I had this pen, it's actually, it's wonderful, I still have it, a LiveScribe™ pen. ...but like, I'm not good at syncing it up, so like once, like the spaces like run out on the pen, um, I don't really know how to like get it back once it's on the computer. ... I used it and it was really helpful ... I feel like if I just spent the time like over break like trying to figure out how to get to it, I might be able to, but then, like I don't really, cause like it saves the dates like messed up... so it's all like messed up. ... So, like it was fine for like the first year but then like now I don't even... they gave me um like this ...tape recorder, like an old fashioned one. But I don't know how to use it. It's sitting in my room. ...I mean I could look at it, like over break and then use it next semester. But like I didn't have time, ...I just didn't have time. I'm not like, I don't like new things. I don't like change. I like routine. (P1 Transcript, lines 277-315).

Lastly, two participants reported qualifying for accommodations they believed would be beneficial but did not use due to fear and anxiety. P3 stated *"I only use it [accommodations] for one class"* (P3 Transcript, line 64), explaining

I didn't give my, uh... accommodations to any other teacher. I felt kinda scared to I guess, and I was worried that um, they were gonna like announce it to the class. And, until like the next year, that I realized when I had one teacher that he had to like, be private about it (P3 Transcript, lines 65-68).

Interestingly, P5 reported only using one accommodation, *extended test time*, not out of fear or anxiety, but because of a belief that the other accommodations would not or could not realistically be provided.

The only one that I've ever really used [accommodation] was the testing [extended time]. But like ... I could take tests orally, short length assignments... A bunch of things that literally

makes things 10 times easier for me but go against every single thing the stereotypical school system stands for.... I've done school my entire life so this is, this is where I am now. And taking a test orally is not something that I've ever seen or heard of, yet I'm apparently accommodated for it" (P5 Transcript, lines 126-135).

Interestingly, both P3 and P5 were diagnosed late in their educational careers, (*"I just got an eval like right before I went to college"* - P3 Transcript, lines 69-70; *"I only got tested for ADHD after my freshman year here [second institution]"* - P5 Transcript, line 62), which may account for their limited understanding of available supports and services.

Perceived Flaws in the System

All five participants found the process by which accommodations were requested and implemented intimidating or frustrating. Feelings of fear, apprehension, frustration and annoyance, particularly as related to self-disclosure and unknown instructor response, were evident in several participant descriptions. As P3's comments illustrate,

I felt some, like some teachers it was a burden to ask for accommodations where others were like, absolutely, like what can I do for you? So, it's kind of, kind of have to like feel out the situation, cause there were times where like I didn't ask, like I didn't get the accommodations cause I felt uncomfortable with the teacher (P3 Transcript, lines 349-352).

Offering a solution to the need for repeated self-disclosure, P5 suggested the following,

In terms of ADA accommodations, whether a student chooses to use them or not, I think that all teachers just should automatically be given them [accommodation letters]. Because uh, the little dilemma in my world is going to get the envelopes and then having to give them to the teacher. ... Like, for one teacher that I have right now, I have had her before but I still need to give her my envelope again ...it just frustrates me (P5 Transcript, lines 440-449).

Disclosure aside, based on participant comments, instructor response or follow-thru was described as a far greater challenge or barrier to effective implementation, and generated concern and apprehension on the part of the students. According to P4's experience,

It's a professor by professor basis. Some are really cool with it [providing accommodations]. Some are really accommodating, and they're like, you know, whatever you need, let, let's make it work. Others are, okay, this is what you requested, we're gonna be very strict, and very to the dot on that. And some are, I don't care. And I have to fight them and be like, no. This is, these are my accommodations. You legally have to give them to me. They're not, yeah, they're literally to level the playing field. But then you do have professors that really go above and beyond (P4 Transcript, lines 145-151).

Similar remarks were made by P5 stating

Neurodiversity... a lot of professors don't know what that is. They weren't raised in an environment which that was a common thing. And it's not normal to them. Just like a lot of things aren't normal to me. And they it, they can't adapt, uh like, some teachers don't understand (P5 Transcript, lines 432-438).

Forgetfulness rather than a lack of understanding appeared to be the difficulty conveyed in P1's description,

So, this one professor... we learned about learning disabilities, you [meaning the professor] work with people who have learning disabilities. He was the worst, literally the worst. There was always a problem. Every time I went to go take the test, wasn't there, didn't work... Like if you say you're going to do something, like actually do it... Like if you say you're going to have the test there at that time, you need to follow through. And then if you say like, alright well you don't have to do this part of the assignment but then like take off points for it... Like you have to write that down and remember it. You can't just take points off and then... so then I had to fight for it... A lot of the times though like professors [in health-related courses] ...were pretty understanding. Like they work with people who need accommodations so they understand (P1 Transcript, lines 460-475).

Pervasive misperceptions about accommodations in general was believed to be a significant factor impacting attitudes (faculty and peer) regarding support services and individuals who need them. As P2 stated,

Giving someone like... an accommodation is not giving them a, an advantage. I've like come across that a lot. ... it's not an advantage, it's just giving someone more of an equal playing ground (P2 Transcript, lines 565-574).

Describing the experience of having to disclose to instructors at the start of every semester, P1 stated

I'm like,...I have this [accommodations letter] for you [instructor]. And they're like, okay thanks. And then like they don't ask anything and I'm just like. Can we talk about it? ...Are you gonna read it? Are you gonna like do anything with it? ...Like, show me that like you're not like interested in it but like, if I have to go to your class and try and understand what you're saying, like, you need to be aware of like how I learn and if it's not working, we need to do something else. ...Sometimes it's just like annoying, and then like some professors were extremely like nice (P1 Transcript, lines 429-437).

This desire for understanding and acceptance was clearly illustrated in P4's advice to faculty:

Try to be really open-minded and understanding. Because it's not easy always on our part to go up and ask for it [accommodations] and to advocate that we need something. Um, understand that if we're asking for something, we're not just doing it because like, eh, we feel like it, there's a reason behind it and you know you don't need to necessarily know that reason but you do need to respect it. ...And just general like, be caring, be understanding of your students (P4 Transcript, lines 333-337).

Necessity is the Mother of Invention

In spite of the challenges reported by participants, each had developed strategies for success beyond the supports provided by disability services. The types of strategies varied based on the unique needs of each participant, but three distinct subthemes were evident: Strategies to support (a) organization and preparation, (b) attention and sensory-regulation, and (c) self-care and self-preservation.

Organization and Preparation

The following comments illustrate participant efforts to meet academic demands, plan and organize assignment completion, exam preparation, and prepare for class. Strategies that were emphasized as particularly helpful included color-coding planners, adhering to false/early due dates to track assignment completion, and using technology to facilitate completion of assigned readings.

I use Washi™ tape to like show like when I have classes. Each class is a different color, and if there's a lab associated with the class it's a light and a dark color. ...If assignments are due, I have circles like on file folders. I write what's due, and I put it on the day it's due, but then move it like a few days ahead so I have it done (P1 Transcript, lines 140-145).

I always try to start everything early. Like I'll get an assignment and I'll be like okay, this is how I need to plan this out...I'll start the research early. I'll get everything set up. And like, I'll give myself like a false due date. (P2 Transcript, line 128-130).

I'll have the computer read it to me. And then I'll highlight things that are like important, and then I'll type out like my questions that I'll have for that day. So, like that's how I get through like the reading (P2 Transcript, lines 201-209).

In addition, P4 stressed the importance of organizing, compiling and maintaining, necessary disability-related documentation to facilitate ease of access and retrieval when needed.

I made a binder, and it had all my neuropsychs, my 504, my IEP's, any information that I could possibly need as a kind of like reference. And I keep that in my room and that way, if I need to look back at something later, it's right there and I don't have to go searching for it. And if people want documentation... I don't have to go searching for it. ...That was helpful (P4 Transcript, lines 318-322).

Attention and Sensory-Regulation

Strategies created by participants with attention and sensory-related difficulties illustrate creativity and perseverance in the development of effective coping strategies. These strategies reflect processing challenges unique to individual students: For instance, P1 used color to increase visual stimulation, engage attention, and focus energy, while P4 briefly closes their eyes to combat sensory overstimulation and increase the ability to concentrate.

I use colorful pens and stickers, cause like black and white like is boring. I can't read what's on this [black and white manuscript page], like it's...all the words are jumbled. ...I have a lot of energy and it's hard for me to like expel my energy when I'm sitting in class for a long amount of time so, I need like colorful things (P1 Transcript, lines 147-155).

I get very overwhelmed sensory wise. ...I'm very sensitive to noise...Whereas most people's brains filter it out... I can't do anything... My brain doesn't [filter it out]. So, I constantly am aware that there are glasses on my face and that, you know I'm wearing clothing, sitting in a chair, and the textures of everything... If they [classrooms] have really strong lights it can be hard. Um, or if they have a bunch of things on the screen at once. It's usually not light as much as the amount of objects,

or... like moving lights... I close my eyes a lot. You know, if I really need to think or just block things out. I close my eyes, and that helps. But... that's also hard because you can't just walk around with your eyes shut, and people don't understand if you just stand there for a minute with your eyes shut. Like... I'm just thinking and not blocking you out (P4 Transcript, lines 233-261).

Unfortunately, in the academic environment, increasing concentration by closing one's eyes may be mistakenly viewed as rude or inattentive. Misperception or misunderstanding of a student's unique challenges was a key concern for several participants. Connecting with instructors was viewed as a vital step in building awareness, and understanding of the cause, as well as the impact, of processing differences on student learning. Speaking on the subject, the following advice was provided by P4:

Talking with my professors the first or second week of class, going to office hours and actually getting to know them... helped a lot. ...You know you're gonna have those weird professors who are stupid. But, you know it made a big difference in that they could... kind of know me and I was able to explain... here's where I'm coming from. This is what works for me, this is what doesn't. Not that I'm expecting you to change everything. But if I do this, I want you to understand that this is why I'm doing it (P4 Transcript, lines 322-329).

Self-Care and Self-Preservation

Successfully navigating the postsecondary environment, several participants emphasized the need for effective self-care strategies, particularly as related to diet, sleep, exercise, and stress management. Offering the following advice to future students, P1 stated *"Take care of yourself...drink enough water, sleep enough. Don't like overdo things...like, you'll get it done eventually[course work]. You don't have to kill yourself, and like get yourself sick over it"* (P1 Transcript, lines 896-898). Diet-related issues were specifically identified by P5 who described weight management difficulties associated with medication use.

I went a year looking like I was like... fresh out of Auschwitz. Because like I didn't have to ... put my arms up to see my ribs and everything because I was taking [named medication] and that just suppressed my appetite (P5 Transcript, lines 73-76).

Addressing this problem, P5 found an effective solution by scheduling a combination of online and in-seat courses, stating

This semester cut my classes down like so significantly that it, there's nothing but time, and that has helped out so much. ...I'm at 12 credits. Two of my classes are online and...two of em are in class... I only have class Tuesday and Thursday. So, Monday, Wednesday, and Friday I have time to go to the gym, eat correctly, then do my work. And I do so much better doing my work after I worked out and after I ate (P5 Transcript, lines 79-85).

Medication usage and management was also problematic for P1, particularly impacting sleep, academic performance, and scheduling of meals.

I take medication to help me focus. I take that in the morning when I wake up. And then it takes like an hour and a half for it to work. So, I wake up extremely early. ...I need that time for my medicine to work. So, I can actually like focus, or like there's no point in me even going. ...But then I do take medicine at night for my anxiety. And I'm supposed to take that with like dinner between like 6:00 to 8:00 [p.m.]. But some days I have classes until 8:30 [p.m.]. So, I don't eat dinner at that time, so I take it when I get back. And then I also take like a sleeping medicine cause like I can't fall asleep cause of the other medicines. So, that's like, I don't really enjoy night classes because of that. Cause if I have a class at 7:45 [a.m.] and then I have like one at 8:30 [p.m.], ...my medicine isn't gonna last that long (P1 Transcript, lines 789-810).

For the majority of participants, stress relief was a daily and ongoing need. A simple environmental change such as the use of Christmas lights rather than traditional lighting in dorm rooms was found to have a comforting effect. However, some stress-relieving strategies required a bit more preplanning and discretion. As P1's statements illustrate,

I have really bad anxiety...I have like little stuffed animals like I always carry like in my bag. Cause like, if I like pet ... like an animal ..., or just like hold it...it helps. ...And... that's why I have like rings, so like I can like spin it if like I get [anxious or stressed], and I can't like just pull out an animal (P1 Transcript, lines 205-212).

P4 also discussed stress-relief through interactions with live animals. *"I find animals and dogs very relaxing and very soothing...when you're really stressed out"* (P4 Transcript, line 209-210). However, P4 believed having an emotional support or service animal would pose too great a distraction from schoolwork stating, if *"you have a choice between like a cat or a dog or homework, like you're gonna pick the animal"* (P4 Transcript, lines 212-213). As a solution, P4 became a regular volunteer at a local animal shelter, walking dogs, taking care of donations, cleaning kennels, and photographing animals ready for adoption.

DISCUSSION

As the aim of this investigation was to examine the lived experience of postsecondary students who identify as neurodiverse, it was necessary to speak with the students directly. Face-to-face interviews following a semi-structured interview guide, provided uniformity while allowing each participant the freedom to describe their unique experiences at length. The three emergent themes, (a) Accommodation Pros and Cons, (b) Perceived Flaws in the System, and (c) Necessity is the Mother of Invention, represent challenges faced by participants, while also highlighting their resiliency, creativity, ingenuity, and determination.

In total, 13 different academic accommodations were identified by participants, but only six were identified as particularly beneficial, and four of those were described as helpful but problematic. *Use of an audio-recording device* allowed students to review lecture material and corresponding

notes at their leisure. However, several participants found this accommodation less than optimal due to technological difficulties and the exorbitant amount of time needed to review content. Additionally, recording lectures in a public forum raises privacy-related concerns as peers may be reluctant to contribute to discussion if they do not wish to be recorded.

Note-sharing was also believed to be helpful, but only if the sharer provided thorough information in a timely fashion. Essentially, the effectiveness of this particular accommodation is directly dependent on the cooperation and diligence of a third-party, who may or may not be fully committed to the process.

Extended time for testing, while a clear stress reliever, was found to be problematic logistically. Scheduling of extended time, particularly for courses that conduct daily quizzes or exams, may require time outside the parameters of the regularly scheduled class. As such, this accommodation adds additional academic burden by significantly decreasing the recipient student's available free time. Finding an extra hour or two for testing may be difficult for students carrying a full course load, and may be near impossible if all courses conducted similar weekly exams. In the scenario described earlier by P1, the student was required to attend the regularly scheduled class, sit and wait while the class completed the exam, and then take the exam at a later time that day – which meant after subsequent classes had ended. This practice added insult to injury, wasting the student's time while outing the student in front of peers. The provision of *extended time for testing* was also routinely referred to as an unfair advantage by peers, a belief clearly reflecting misperceptions regarding accommodations and the individuals who use them.

Negative experiences with peers and faculty prompted several participants to weigh the potential benefits of accommodation use with perceived associated negative side-effects: embarrassment, fear, anxiety, and increased stress. As a result, some participants chose to selectively implement accommodations in a particular course or with a specific professor, while others attempted to hide the use of supports, or forego use entirely.

Considered a significant flaw in the system, the need for repeated self-disclosure and self-advocacy was universally viewed as unfair, unnecessary, and demeaning. Students were extremely reluctant to approach instructors at the start of each semester, and clearly fearful their needs would not be understood or met. To be fair, the participants also described positive experiences with particular faculty, however the fear of encountering a potential negative response was pervasive. Participants repeatedly emphasized a desire to dispel negative misperceptions regarding accommodation use, and foster an environment of acceptance and willingness to collaborate.

Lastly, participants disclosed the need to develop strategies for success beyond those provided through the institution's disability services. Organization-based strategies with an emphasis on preparedness were identified, including: compiling and maintaining disability-related documentation, color-coding, use of false due dates, and technology assisted reading. In

addition, strategies such as using colorful pens and stickers to increase and engage attention, compared to momentarily closing one's eyes and using soft lighting to combat sensory overload illustrate the diverse and unique differences between individuals who are neurodiverse. Participant statements clearly emphasize the importance of attention to self-care, particularly for those managing medications, including maintaining a healthy diet, sleep schedule, exercise regimen, and manageable course load and schedule.

At the time of interview, all five participants were reportedly successful in their current area of study but experienced significant levels of stress, frustration, and anxiety. Supports meant to minimize these adverse effects were described in positive and negative terms: simultaneously identified as beneficial, helpful, frustrating, annoying, and stigmatizing. In addition, interactions with peers and faculty were often experienced as stressful and frustrating. Participants clearly expressed a desire for understanding and acceptance, and a greater awareness of neurodiversity as a difference rather than a stigmatizing detriment or excuse to gain preferential treatment.

Limitations and Future Research

The findings in this study represent the lived experience of five postsecondary students, attending a small, private, liberal arts postsecondary institution located in southeastern, Pennsylvania. Therefore, a key limitation to the investigation is the small sample size and restricted geographic location from which the participants were drawn. While all participants self-identified as neurodiverse, and were registered with the school's disability service, diagnoses and accompanying challenges differed greatly across individuals. Additionally, all participants were full-time students, primarily enrolled in on-site courses. Data therefore does not represent the experience of students enrolled in on-line programs.

While the size and heterogenous characteristics of the sample limits generalizability, the results do corroborate earlier findings linking perceived stigma to students' reluctance to self-disclose, self-advocate, and use accommodations in general (Cole & Cawthon, 2015; Roux et al., 2015; Van Hees, Moyson Roeyers, 2015). Findings also support the need for faculty development opportunities, including information regarding neurodiverse conditions, strategies to facilitate accommodation implementation, and accessible instructional methods (Burstahler & Russo-Gleicher, 2015; Cole & Cawthon, 2015).

Future research is also needed to examine the existence of negative bias toward students with neurodiverse conditions and identify methods for elimination in the postsecondary community and, by extension, community at large. The development of peer mentorship programs, pairing junior, senior, or graduate level neurodiverse students with their underclassman counterparts, may also prove beneficial; allowing seasoned students to serve as role models and mentors. Research is necessary to examine the feasibility of such programs including the willingness of mentor and mentees to participate, and identification of appropriate preparatory supports for mentors.

CONCLUSIONS

Findings from this investigation represent a first-hand accounting of the experience of five unique postsecondary students who identify as neurodiverse. Although sample size and characteristics limit generalizability, the data corroborates findings from earlier investigations regarding reluctance to self-disclose, self-advocate, and use accommodations in general, perceived stigma, and the need for faculty supports. Ideally, insights garnered from this investigation will contribute to a greater understanding and awareness of neurodiverse students in the postsecondary environment, and stimulate further inquiry into current and novel support service provisions, including the potential for peer mentorship and instructor training, and strategies for eliminating disability related stigma and bias in the postsecondary environment.

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REFERENCES

- Americans with Disabilities Act (1990). Retrieved from http://www.ada.gov/2010_regs.htm
- Burgstahler, S. & Russo-Gleicher, R. (2015). Applying universal design to address the needs of postsecondary students on the autism spectrum. *Journal of Postsecondary Education and Disability*, 28(2), 199-212.
- Cole, E., & Cawthon, S. (2015). Self-disclosure decisions of university students with learning disabilities. *Journal of Postsecondary Education and Disability*, 28(2), 163-179.
- Daly-Cano, M., Vaccaro, A., & Newman, B. (2015). College student narratives about learning and using self-advocacy skills. *Journal of Postsecondary Education and Disability*, 28(2), 213-227.
- Gelbar, N., Smith, I., & Reichow, B. (2014). Systematic review of articles describing experience and supports of individuals with autism enrolled in college and university programs. *Journal of Autism and Developmental Disorders*, 44, 2593-2601.
- Hassel, S. & Ridout, N. (2018). An investigation of first-year students' and lecturers' expectations of university education. *Frontiers in Psychology*, 2017, 8, 2218. Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5790796/>
- Houting, J. (2019). Neurodiversity: An insider's perspective. *Autism*, 23(2), 271-273. doi:10.1177/1362361318820762
- Hycner, R. (1985). Some guidelines for the phenomenological analysis of interview data. *Human Studies*, 8, 279-303.
- Kraglund-Gauthier, W., Young, D., & Kell, E. (2014). Teaching students with disabilities in post-secondary landscapes: navigating elements of inclusion, differentiation, universal design for learning, and technology. *Transformative Dialogues: Teaching and Learning Journal*, 7(3), 1-9.
- Longtin, S. (2014). Using the college infrastructure to support students on the autism spectrum. *Journal of Postsecondary Education and Disability*, 21(1), 63-72.
- McGregor, K., Langenfeld, N., Van Horne, S., Oleson, J., Anson, M., & Jacobson, W. (2016). The university experiences of students with learning disabilities. *Learning Disabilities Research & Practice*, 31(2), 90-102. doi: 10.1111/ldrp.12102
- Pitt, A., Opreescu, F., Tapia, G., & Gray, M. (2018). An exploratory study of students' weekly stress levels and sources of stress during the semester. *Active Learning in Higher Education*, 19(1), 61-75. doi:10.1177/1469787417731194
- Roux, A., Shattuck, P., Rast, J., Rava, J., Edwards, A., Wei, X., ... Yu, J. (2015). Characteristics of two-year college students on the autism spectrum and their support services experiences. *Autism Research and Treatment*, 2015. Retrieved from doi: 10.1155/2015/391693
- Section 504 C of Rehabilitation Act. Retrieved from <http://www.dol.gov/oasam/regs/statutes/sec504.htm#UPCABLz pJM>
- Shmulsky, S., Gobbo, K., & Donahue, A. (2015). Groundwork for success: A college transition program for students with ASD. *Journal of Postsecondary Education and Disability*, (28), 235-241
- United States Department of Education (2000). A guide to the individualized education program. Retrieved from <https://www2.ed.gov/parents/needs/speced/iepguide/iepguide.pdf>
- Van Hees, V., Moyson, T., & Roeyers, H. (2015). Higher education experiences of students with autism spectrum disorder: Challenges, benefits and support needs. *Journal of Autism and Developmental Disorders*, 45, 1673-1688.

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