

**Facilitators and Barriers of Autistic Students' Experiences:**

**An Exploratory Thematic Analysis**

BY

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THESIS

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This thesis is dedicated to my parents, Eric and Amy Rottier, for their constant love and support. This thesis is also dedicated to the countless autistic, neurodivergent, and disabled students who make this work possible.

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HR

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## **LIST OF ABBREVIATIONS**

ADHD	Attention Deficit Hyperactivity Disorder
ASAN	Autistic Self Advocacy Network
ASD	Autism Spectrum Disorder
EAPS	Experiences of Autistic Postsecondary Students Survey
LGBTQ+	Lesbian, Gay, Bisexual, Transgender, Queer, Plus



## **SUMMARY**

A study of autistic and neurodivergent students' experiences was conducted. An online survey was distributed via listservs and social media and 160 participants completed valid responses. Information on demographics and student status, disability identity, and past and current educational experiences was collected. Open-ended responses on facilitators, barriers, and resources were coded and sorted using thematic analysis.

Facilitators to student success and satisfaction included opportunities, relationships, and accommodations. Barriers included disability-related barriers, socialization, and academics. Resources included accommodations, mental health services, and academic support services such as tutoring, advising, and library services.

Findings from this research should set future research priorities on autistic and neurodivergent students' experiences, especially on accommodations, and guide support services for autistic and neurodivergent postsecondary students. Further research should also include more representative participant samples and compare neurodivergent student experiences to those of neurotypical students.

## **ABSTRACT**

Autistic and neurodivergent students are graduating from high school and entering postsecondary education at increasing rates; it is estimated that 1-2% of all postsecondary students in the US meet criteria for autism, and even more have other neurodivergent conditions like attention deficit hyperactivity disorder (ADHD), learning disabilities, and psychiatric disabilities. This growing student population has unique needs, challenges, and experiences in higher education. Increasingly, colleges and universities are offering disability services and other dedicated supports to meet the needs of autistic and neurodivergent students. However, most of the research on these students' experiences comes from the perspective of parents, educators, administrators, and other professionals, rather than from the students themselves. Additionally, most research focuses on deficits and challenges, with little research exploring positive aspects of campus life for disabled students. This thesis centers student perspectives on strategies to promote success and satisfaction in higher education. Responses were collected from a national online survey of enrolled autistic and neurodivergent students across the United States conducted in 2019. The survey included qualitative questions on positive and negative aspects of students' college life. Using thematic analysis, I identified facilitators, barriers, and resources that impact neurodivergent students' experiences. Key facilitators included opportunities for exploration and personal growth and relationships with mentors, peers, and communities, while key barriers included disability-related discrimination, mental health, and socialization. Accommodations emerged as both a facilitator and barrier. Students also reported using academic support resources more frequently and effectively than

specific disability resources. This research has implications for student support programs, especially accommodations and disability services, and can be used to direct students toward effective resources and strategies for navigating higher education.

## I. INTRODUCTION

### A. **Background**

Autism, or autism spectrum disorder (ASD) is a neurological condition and developmental disability characterized by a spectrum of differences in social communication and interaction, extreme sensory experiences, intense passions or interests, and repetitive behaviors (Autistic Self Advocacy Network [ASAN], n.d.a; American Psychiatric Association, 2013). According to the Center for Disease Control (2019), one in 59 children is diagnosed with autism, but it is estimated that many more adults and children meet criteria for the developmental disability (Wiggins et al., 2020). Rising prevalence has incited fears of an autism epidemic, but research shows that increased prevalence may be attributed to increased awareness and developmental screening, diagnostic expansion, and diagnostic access to services (Graf et al., 2017).

While some individuals and organizations treat autism like a crisis or disease, it is important to understand that many autistic individuals view autism as part of their identity, culture, and as a source of pride. Following the social model of disability, which shifts the need to change from curing individual bodies to the ensuring accessibility in the built environment, autistic self-advocates and allies call for access and inclusion over cure and normalization (Oliver, 1996; Woods, 2017). Neurodiversity is the political movement that recognizes the value of diverse minds and ways of being, one that eschews cure and rehabilitation for cognitive and neurological disabilities and prioritizes support and acceptance to allow neurodivergent individuals, including those with autism and related disabilities, to thrive (Kapp et al., 2013; den Houting, 2019). Organizations

like the Autistic Self Advocacy Network work to empower and support autistic individuals and communities through policy, resources, and leadership.

Though there has been an increase in autistic individuals being diagnosed in adulthood (Jensen et al., 2014), most autistic people are identified in childhood and over half receive early intervention and special education services throughout primary and secondary school provided through the Individuals with Disabilities Education Act (IDEA, 2004; McDonald et al., 2019). Thus, as adolescents transition into adulthood, they are faced with a sudden decline in available services, nicknamed the “services cliff” (Roux et al., 2015). Lack of services coupled with low rates of further education and employment paint a bleak picture for autistic adults. However, postsecondary education engagement has been shown to significantly improve outcomes for autistic adults, including employment, community participation, and quality of life (Hendrickson et al., 2013; Plotner & May, 2019).

As increasing numbers of autistic young adults graduate from high school and enter college, campuses are faced with a new student population in need of support. While many autistic students are academically capable of succeeding in postsecondary education, they struggle with other aspects of the transition to college, including navigating social situations, advocating for accommodations, and managing their mental health (Ames et al., 2016; Anderson et al., 2017; Jackson et al., 2018).

## **B. Statement of Problem**

Even as the number of autistic college students increases, enrollment and graduation rates for autistic students still lag behind those of D/deaf and hard of hearing students and students with visual impairment, speech/language impairment, and

learning disabilities (Sanford et al., 2011), making clear the need for additional supports to address the unique challenges faced by autistic students.

In the past decade, research and services for autistic college students have skyrocketed, with some notable gaps, particularly in their failure to consult autistic students to understand their needs and perspectives (Sarrett, 2018). Instead, previous research has centered the perspectives of educators, administrators, parents, and other non-autistic professionals (Barnhill, 2016; Elias & White, 2018). Research that does include student participants is limited by small to moderate sample sizes and single institution selection strategies (Accardo et al., 2019; Gelbar et al., 2015; Kuder & Accardo, 2018). Failure to research autistic student perspectives not only impacts the effective development and implementation of support services, but also threatens the integrity of all postsecondary education autism research, as the autistic community, in chorus with the wider disability rights community, advocates “Nothing about us, without us” (ASAN, n.d.b.; Charlton, 1998).

### C. **Purpose of Study**

This study seeks to address gaps in previous literature by collecting the perspectives of autistic and neurodivergent postsecondary students. Neurodivergence encompasses autistic students, but also students with ADHD, learning disabilities, psychiatric disabilities, and other cognitive and neurological disabilities and differences. Neurodivergent students demonstrate similar strengths, challenges, and needs in higher education (Gillespie-Lynch et al., 2017). Including neurodivergent students allows students to identify more broadly, beyond diagnostic labels, and yields research that is applicable to students with cognitive and neurological disabilities.

By understanding the unique experiences of this student population, we can better design and implement the resources and supports that will enable them to succeed. This study also included participants from across the United States, representing 65 different postsecondary institutions including community and technical colleges and public and private universities, and seeking certificates, Associate, Bachelors, Masters, doctoral, and professional degrees. Thus, findings from this study encompass a range of postsecondary education experiences.

While most research on postsecondary experiences addresses barriers and obstacles, it is equally important to understand what components of postsecondary education promote positive student experiences. For this reason, this study asked the following three questions:

1. What do autistic and neurodivergent students report as facilitators to student success and satisfaction in postsecondary education?
2. What do autistic and neurodivergent students report as barriers to student success and satisfaction in postsecondary education?
3. What do autistic and neurodivergent students perceive as useful resources in postsecondary education?

For the purposes of this study, success refers to students' academic achievement and progress as well as their social, emotional, and physical well-being on campus.

Satisfaction refers to students' contentment with their educational experience.

Additionally, this study will analyze how certain factors can serve both as facilitators and

barriers and examine how this overlap complicates life and education for autistic and neurodivergent students.



## II. BACKGROUND

### A. Conceptual Framework

#### 1. Neurodiversity

Neurodiversity is a paradigm and political movement asserting the value of different ways of knowing, thinking, and being associated with neurodivergent conditions including autism, ADHD, and psychiatric and cognitive disabilities (Kapp, 2020). Neurodiversity draws upon the social model of disability in the context of neurological disabilities; Woods (2017) explores how the social model can be “re-invigorated for autism” and other neurodivergent conditions through changes to the social environment, influencing the attitudes of the neurotypical population towards neurodivergent people and communities (for more on the social model of disability, see Oliver, 1996). Robertson (2010) explains neurodiversity as an alternative to deficit-based models of autism and other neurodivergent conditions. Instead, neurodiversity recognizes the unique strengths and challenges of neurodivergent people, advocating for increased support and improved quality of life.

Neurodiversity emerged from autistic self-advocates in the 1990s and has risen to mainstream and academic acclaim in the past decade (Kapp, 2020; Robertson & Ne’eman, 2008). Accompanying this rise in popularity are numerous misconceptions and critiques of the movement; Jac den Houting (2019) responds to criticisms by addressing myths about neurodiversity. First, den Houting argues that rather than rejecting disability, neurodiversity proponents embrace the social and social-relational models of disability. Kapp et al. (2013) draw the same conclusion in their article entitled,

*Deficit, Difference, or Both?*, arguing that autism and other neurodivergent conditions are indeed disabilities and that disability isn't inherently tragic.

Second, den Houting (2019) explains that neurodiversity is for everyone, not just those with low support needs, often referred to as "high functioning." Functioning labels have been rejected by the neurodivergent community because they fail to communicate meaningful information and often draw upon ableist expectations, such as perceived intelligence or verbal speech. Additionally, as Ellen Murray (2016) shared on Twitter, "High functioning' is used to deny support. 'Low functioning' is used to deny agency." Functioning labels are used to stigmatize and withhold resources from neurodivergent and disabled people. Finally, den Houting argues that while neurodiversity proponents often reject cure and normalization, the same proponents are in favor of supports that allow neurodivergent people to thrive. Kapp et al. (2013) similarly address neurodivergent conditions, and autism, as sources of challenges as well as strengths.

Neurodiversity as a paradigm and political movement critically influences my work as I strive to center neurodivergent perspectives to understand the unique challenges, strengths, and needs of neurodivergent students. My work uses neurodiversity and the disability community's rallying cry, "Nothing about us, without us!" to address gaps in existing research on neurodivergent student experiences. Neurodiversity demands an accepting, supportive environment that allows neurodivergent people to thrive, and my research seeks to understand how students access such support to facilitate satisfaction and success in higher education.

## 2. **Academic ableism**

My work draws substantially from previous research on the experiences of disabled students and faculty in higher education. Emerging from disability studies and using the social model of disability as a framework, this research focuses on how the academic environment excludes disabled students, faculty, and scholars. Jay Dolmage's (2017) *Academic Ableism* analyzes how ableism is manufactured and perpetuated through postsecondary education. Dolmage explains that disability exists in opposition to the ideals of the academia and highlights how academia obscures and deflects disability at the expense of disabled students and faculty, portraying disability as an individual failing rather than a source of systematic oppression. Finally, Dolmage addresses current bureaucratic responses to disability such as academic accommodations, technology bans, and campus mental health campaigns, articulating the perils and inequity inherent in these responses. Margaret Price's (2011) *Mad at School* similarly examines disability and specifically mental disability and neurodivergence in the context of academia. Price identifies topoi of academia and the resistance and resilience of mentally disabled students and faculty in adhering to or failing to adhere to these topoi. Price theorizes kairotic space, the social emotional pressures and expectations of academic environments, and fluency in such spaces as especially challenging for neurodivergent individuals. Collegiality, too, requires ablenormative socialization, social enjoyment, and social habits such as eating and drinking alcohol, posing additional barriers for neurodivergent academics. Both books examine barriers to disabled academics' participation and success in academia.

My work also incorporates existing research and practices to support autistic and neurodivergent college students. Duggan's (2017) *First Class Support for College Students on the Autism Spectrum* is written by and for college educators, while the Autistic Self-Advocacy Network's (2013) *Navigating College* is written by and for autistic students. Both books provide guidance on academic, social, and independent living skills and physical and mental well-being. Additionally, both books focus on "taking the seemingly multicomplex world of higher education and making it quantifiable and organized" (Duggan, 2017, p. 28) to improve outcomes for autistic students. The authors use personal experiences to illuminate supports and strategies that facilitate student success.

My work draws upon existing research to understand academia as an institution, examine academic ableism and inequity, and improve support for autistic and neurodivergent students. Focusing on academic ableism and external barriers and supports collides with neurodiversity and the social model of disability to remove the "problem" of disability from the disabled student. Guided by the preceding works, I strive to understand the experiences of neurodivergent students on college campuses across the country.

## B. **Literature Review**

### 1. **Importance of postsecondary education**

Attending and graduating from postsecondary education are pivotal milestones in the lives of many young adults and have notable benefits; in addition to higher pay and increased job security, college graduates experience higher job satisfaction, longer life expectancy, and increased community engagement, health, and

happiness (Center for Disease Control, 2012; Pew Research Center, 2014; Trostel, 2015). While little research exists, it is believed that these positive outcomes are even greater for young adults with disabilities (Hendrickson et al., 2013). Plotner and May (2019) articulated postsecondary education as a gateway to independence, self-determination, community integration, and improved quality of life for adults with developmental and learning disabilities. Because of its potential to improve outcomes in areas including employment, independent living, self-advocacy, and overall well-being, it is critical that higher education be made accessible to students with disabilities, including autistic and neurodivergent students.

## 2. **Enrollment and completion rates**

Increased identification, diagnosis, and support of autistic children corresponds to increased autistic young adults graduating from high school and entering postsecondary education (Gurbuz et al., 2019; Roux et al., 2015). However, autistic students still enroll in and complete higher education at much lower rates than their non-autistic peers. The National Longitudinal Transition Survey (NLTS-2) follows adolescents in the years following high school graduation to track outcomes for students with and without disabilities, as identified by secondary education Individual Education Plans. The following statistics are gleaned from the NLTS-2. First, 36% of autistic young adults attend postsecondary education in the years immediately following high school completion, compared to 75% of young adults in the general population. Additionally, autistic young adults have lower postsecondary education enrollment than their peers with other disabilities, including speech/language impairment, learning disabilities, and physical disabilities (Roux et al., 2015). Among autistic young adults who enrolled in

postsecondary education, 70% ever attended a two-year community or technical college, while 32% ever attended a four-year college or university (Roux et al., 2015). Thus, community college provides critical educational opportunities to autistic and disabled young adults. Finally, autistic students had a postsecondary completion rate of 38.8%, compared to 60% among students in the general population (Newman et al., 2011). All these statistics indicate the need for increased support for autistic postsecondary students.

While previous research has estimated that 1-2% of all college students meet criteria for autism (White et al., 2011), it is difficult to estimate the prevalence of autism among college students due to underdiagnosis of women, minorities, and adults and lack of disclosure among students who do not seek services (Ames et al., 2016). Nevertheless, autistic students represent more than an incidental proportion of college students. More recent studies have reported on neurodivergent students, allowing students with similar strengths, challenges, and support needs to identify beyond the autism label (Gillespie-Lynch et al., 2017). Increases in students identifying as neurodivergent create a more pressing need for support to these students.

### 3. **Transition and support programs**

The increased needs of autistic and neurodivergent students have been accompanied by an increase in transition and support programs designed to equip and empower these students towards postsecondary success. Most programs focus on goals including integration into the college or university, promoting postsecondary completion and employment, and increasing community engagement. Programs achieve these goals through mentoring, structured social opportunities, transition and

orientation assistance, and training in key areas including academics and study skills, social skills, independent living, and executive functioning (Hurley-Hanson, 2020). Evaluations of individual programs have yielded mixed results and identified some common challenges faced by autistic and neurodivergent students.

Ames et al. (2016) used student feedback to assess the ASD Mentorship Program (AMP), a peer mentoring model grounded in disability theory, at York University. Students retroactively identified goals that they achieved through the program, with the most common goals related to social skills and mental health. Overall, students were satisfied with the program and noted the benefits of meeting individually with peer mentors. Additionally, 80% of participants indicated that the AMP helped them achieve their goals. Interestingly, most students accessed AMP in their second year of university, despite the program's aim to assist students with the transition to college in their first year. Ames et al. recommended increased focus on social skills, co-occurring mental health issues, and the transition from college to the workforce in future support programs.

Hillier et al. (2018) conducted a similar evaluation, using self-report measures to track participants' self-esteem, loneliness, and mental well-being before and after the intervention. The group design consisted of a seven-week small group curriculum focused on study skills, social skills, and time management. Participants reported increased self-esteem and decreased loneliness and generalized anxiety following the group. Additionally, a significant number of participants reported making friends within the group setting.

Rowe et al. (2020) identified three areas where autistic students need additional support: social skills, independent living skills, and career development. To meet these needs, they implemented a peer-mentoring program and used individual student self-report to identify goals. Staff reported that students increased their confidence and self-advocacy skills over the duration of the program.

Lucas and James (2018) used mixed methods to capture the experiences of both mentors and mentees in a specialist mentoring program for autistic students and students with mental health conditions. This program employed professional mentors rather than peer mentors. Student mentees completed questionnaires and interviews regarding their experiences with mentorship, with autistic students reporting overall satisfaction and significant improvements in academic and social skills.

Lei et al. (2018) evaluated a pre-college transition program designed to ease autistic students' anxiety and fears around attending college. Researchers used student satisfaction and ratings of concern regarding the transition to college to analyze the program. Student concerns decreased significantly after attending the transition program. Researchers also asked students what they are looking forward to in college: answers included education/courses, new social opportunities, and increased independence.

While previous programs were designed by educators and other professionals and evaluations included student perspectives, Gillespie-Lynch et al. (2017) incorporated student perspectives into their program design. Prior research identified needs related to social skills, self-advocacy, and executive functioning, so researchers designed curricula around these topics, informed by needs-assessments completed by



participating students. Students also completed written evaluations and focus groups at the end of each term. The self-advocacy curriculum was especially indicated as beneficial to students. However, Gillespie-Lynch et al. pointed out that the opportunity to engage with peers in a structured environment may be even more beneficial than any designed curricula.

There are also three systematic reviews on evaluations of transition and support programs for autistic students. Toor et al. (2016) reviewed twelve qualitative studies on transition to college for autistic students. They identified six themes: involvement of professionals, academic factors, environmental factors, social factors, independent living, and self-advocacy. Academic factors including accommodations, increased flexibility, and interest in educational opportunities served as facilitators of students' transition to college. Environmental and social factors and difficulty with independent living were noted as barriers to students' transition. Toor et al. emphasized the importance of including student, parent, and professional perspectives in research on autistic students in higher education.

The second review, from Kuder and Accardo (2018), examined eight studies that included cognitive-behavioral interventions, social communication interventions, a college transition program, and academic accommodations. Kuder and Accardo acknowledged the limited data and mixed results of these studies, stating that while emerging literature has set the stage, there is more work to be done to ensure transition and support programs are effective. They also emphasized the importance of individualized supports for students. The third review, from Nachman (2020), examined seven studies on college transition programs. Analysis yielded common themes

embedded in program curricula, especially around social skills and self-advocacy. Six of the seven programs implemented peer mentoring with other undergraduate or graduate student mentors. Nachman noted that mentors have varying levels of training and familiarity with autism, and none of the programs employed autistic peer mentors to guide autistic students. Nachman also pointed out the absence of critical disability theory and intersectionality in the program design and evaluation and recommended incorporating both to enhance transition programs.

Common challenges faced by autistic and neurodivergent college students that emerged from these studies include social skills, independent living skills, academic and study skills, mental health and stress, and the transition from college to employment. Programs helped students improve their academic skills, social skills, confidence, self-advocacy skills, and overall well-being. The studies are limited by small sample sizes, single program evaluations, and lack of long-term program outcome data. However, these studies set the stage for further research on parent, professional, and student perspectives on autism in college.

#### 4. **Parent and professional perspectives**

In the past decade, there has also been an increase of research on parent and professional perspectives regarding autistic students' transition and success in college. As in disability advocacy, parents and professionals represent key stakeholders in research and practice to support autistic students (see Leiter, 2012). Thus, it is critical to understand parent and professional perspectives to understand the interventions and support services in place for autistic students.

Elias and White (2018) conducted an online survey of parents of autistic young adults (N = 52) that sought to identify strengths, challenges, and needs for autistic students' success in postsecondary education. Parents articulated challenges with social interaction, independent living skills, self-advocacy, and managing emotions. Elias and White also emphasized parent involvement in the transition to postsecondary education as key to student success.

Researchers have also examined faculty perspectives on autistic students' strengths and challenges in postsecondary education. As Gobbo and Shmulsky (2014) explain, faculty directly observe student behavior in the classroom and help to determine whether students succeed or fail in postsecondary education, making faculty perspectives critical to autistic students' success. Gobbo and Shmulsky conducted focus groups with faculty (N = 18) at a small college designed for neurodivergent students. Faculty reported that autistic students had difficulties with social understanding, critical thinking, and high levels of anxiety and noted students' strengths including passionate interests, the desire to learn, and adherence to clear rules. McKeon et al. (2013) conducted a similar study, surveying faculty (N = 69) at one private university. Faculty reported student difficulties with communication and executive functioning. Both studies reported on promising teaching strategies for autistic students; these included providing structure in the classroom, providing support for long-term assignments, implementing accommodations, and attending to the emotional climate in the classroom.

More recently, a study by Hassenfeldt et al. (2019) surveyed graduate teaching assistants (N = 92) on their knowledge of autism and their confidence instructing autistic

students. Teaching assistants demonstrated moderate knowledge of autism, but only 15% felt confident instructing autistic students, and 97% reported that they received no training on autism. Hassenfeldt et al. and McKeon et al. recommended increased training for instructors on working with autistic students.

Rather than surveying faculty, Barnhill (2016) surveyed multiple institutions of higher education to identify current practices and supports offered to autistic students. In line with parent and professional perspectives and the priorities of existing transition programs, most campuses offer social skills interventions and structured social opportunities, independent living and executive functioning skills, and peer mentoring. Colleges also offer a range of academic accommodations including testing accommodations, notetaking, and tutoring. Barnhill highlighted asking students what they need and tailoring support to these needs. Obtaining student perspectives is the best way to understand and support autistic students.

## 5. **Student perspectives**

While early research and interventions relied on the perspectives of parents and professionals, there has been an increase in research on the perspectives of autistic students themselves. Centering autistic students is critical to ensuring self-determined and effective support programs and in aligning postsecondary education research with the goals of disability advocacy and disability studies, which claim “Nothing about us, without us.” As Ari Ne’eman wrote in the introduction to Navigating College:

Still, this book is different in some important ways. It is written by Autistic people ourselves, rather than professionals or family members. This distinction is key –

we know our own needs better than those who speak for and to us. (ASAN, 2013, p. 3)

Sarrett (2018) made the same distinction in her call for increased research centering autistic student perspectives, highlighting that challenges and supports have primarily been identified and implemented by parents and professionals. Sarrett proposed that shifting towards student perspectives will also shift priorities toward positive identity development, mental health, and campus acceptance of autistic students. In the past five years, researchers have conducted several studies to begin identifying student perspectives on strengths, challenges, and support needs in postsecondary education.

Van Hees et al. (2015) interviewed current and former autistic college students (N = 23) on education, student life, and independent living. Students reported challenges with unexpected changes to structure and routine, social interaction, executive functioning, disclosure of their disability status, and mental health issues. Students also provided recommendations including personalized supports, academic accommodations, psychosocial support, and adequate leisure and rest. Van Hees et al. also noted the need for increased awareness and training on autism and neurodiversity in higher education settings.

Gelbar et al. (2015) conducted an online survey of current and former autistic college students (N = 35) and found that although students reported high rates of academic success, they also experienced difficulty with executive functioning, loneliness, and coping with stress and anxiety. Because the survey targeted active self-advocates, there were high rates of accommodation use and comfort with self-advocacy. Gelbar et al. acknowledged the role of academic accommodations in

facilitating academic success and the need for similar accommodations or supports to address independent living and social skills.

Accardo (2017) collected responses from incoming autistic college students (N = 14) on defining and obtaining success in postsecondary education (note that these students were enrolled but had not started college at the time of the study). Students identified four indicators of success: achieving good grades, having a sense of self-efficacy, participating socially on campus, and eventually, graduating. Incoming students reported that support from parents and family members was a facilitator to success, while poor mental health was a barrier. Accardo recommended further research to design and implement effective and inviting interventions to support autistic students' psychosocial development.

Anderson et al. (2018) conducted an online survey of autistic undergraduate and graduate students in Australia (N = 48). Students ranked their perceived strengths and difficulties and relayed their utilization and satisfaction with support services. The highest ranked strengths were attention to detail, aptitude for technology, creativity, memory, and consistency, while the highest ranked difficulties were anxiety and depression, loneliness, and sensory issues. Anderson et al. noted underutilization of services, even though participants were overall satisfied with services. Academic accommodations were endorsed as the most helpful supports, while few students reported high satisfaction with non-academic and autism-specific supports. Anderson et al. proposed incorporating strengths-based and universal design for learning approaches to make college more accessible to autistic students, especially those unwilling to disclose to obtain supports and those unaware of their autism status.

Jackson et al. (2018) also conducted an online survey of enrolled autistic students in the US (N = 56), answering questions about their academic and social experiences and mental well-being. Participants indicated that they were slightly to very comfortable with academics and reported using a range of student services including academic advising and accommodations. Several participants reported experiencing loneliness, exclusion, and isolation, despite a range of satisfaction with social experiences. Participants experienced severe depression, anxiety, and stress, with a high rate of suicidal thoughts and behavior. Jackson et al. recommended increased psychological services to meet the emotional needs of this student population.

Another study from Accardo et al. (2019) surveyed autistic students registered with disability services at one institution (N = 23). Students responded to items about accommodation and services utilization and preferences. Student-preferred accommodations included extended testing time, professor's lecture notes, and priority registration, while preferred student services included academic coaching, tutoring, and access to the writing center. Autistic students did not demonstrate a preference for autism-specific services such as peer mentoring, support group, social skills, and self-advocacy training. Accardo et al. emphasized the need for personalized support to meet individual students' needs.

Finally, McLeod et al. (2019) conducted an online survey comparing autistic students (N = 100) to their neurotypical peers in the state of Indiana. They found that autistic students were less likely to participate in internships and field placements as part of their college education. Additionally, autistic students reported lower sense of belonging and social quality and higher rates of social bullying and exclusion than

students with and without disabilities. McLeod et al. recommended anti-bullying and anti-stigma campaigns to educate neurotypical students about their autistic peers and noted health disparities, particularly in mental health, that require additional support on campus.

The studies described used student perspectives to identify the strengths, challenges, needs, and preferences of autistic college students. Autistic students demonstrated strengths with high levels of academic success, attention to detail, creativity, consistency, and resilience. However, autistic students also face numerous challenges, including poor mental health and stress, executive functioning, loneliness, exclusion, and bullying, and sensory issues. Additionally, autistic students tend to underutilize support services and accommodations and demonstrate little preference and perceived benefit from autism-specific interventions. Limitations of past studies include small sample sizes and single-institution designs. Additionally, in all the studies described, participants were required to disclose their formal diagnosis of an autism spectrum disorder. Requiring formal diagnosis excludes undiagnosed autistic students who may not have medical or financial access to a diagnosis and skews the sample towards white male participants who are diagnosed more frequently and accurately than autistic individuals of other races and genders. Finally, many of the studies accessed students through disability services offices, which excludes students who do not disclose or register for services. The present study seeks to mitigate these limitations through its inclusion criteria and sampling strategy.



### III. METHODS

#### A. **Design**

The data presented here is from the Experiences of Autistic and Neurodivergent Postsecondary Students (EAPS) Survey, initially conducted as the Experiences of Autistic University Students Survey. This study is exploratory in nature and used a mixed-methods survey design to answer questions about autistic and neurodivergent students' experiences, needs, and preferences.

#### B. **Participants**

Eligible participants were over the age of 18 years, currently enrolled at a postsecondary institution located in the United States, and identified as autistic, neurodivergent, or as having ADHD, psychiatric disabilities, or other related conditions. Participants were recruited online via email, Facebook, and Twitter, with links to the online survey being shared by colleges and universities, campus disability services, autistic advocacy organizations, and individual advocates and allies. There were over 300 initial responses to the survey. Responses were included as valid if participants indicated that they were currently enrolled at a postsecondary institution located in the United States and participants completed and submitted the survey ( $n = 160$ ). Coherent responses to the open-ended questions served as another quality check. Additionally, all 160 participants identified themselves as autistic, neurodivergent, and/or disabled. Of the 160 participants, 100 indicated they were undergraduate students and 60 indicated they were graduate or professional students. Over half of participants were age 18-23, with another 20% of participants reporting they were 30 years or older, indicating that while most participants were traditional-age college students, the sample also included

nontraditional or returning students. The sample was predominantly white (n = 130, 81.3%), with few participants identifying as Asian (n = 4), Black (n = 2), Latinx (n = 3), multiracial (n = 14), and other races (n = 6). Most participants were cisgender women (n = 85, 53.1%), followed by cisgender men (n = 31), non-binary (n = 25), transgender women (n = 11), and transgender men (n = 7). Participants' sexual orientation varied: heterosexual (n = 60), bisexual (n = 31), queer (n = 25), asexual (n = 19), homosexual/gay/lesbian (n = 13), pansexual (n = 7), questioning (n = 2), and other sexual orientation (n = 1). Participant demographics are listed in Table I.

TABLE I

## PARTICIPANT DEMOGRAPHICS

		<b>n</b>	<b>%</b>
<b>Student Status<sup>1</sup></b>	Undergraduate	100	62.5
	Graduate	60	37.5
<b>Age<sup>2</sup></b>	18-20	41	25.6
	21-23	44	27.5
	24-26	26	16.3
	27-29	15	9.4
	30+	33	20.6
<b>Race/Ethnicity<sup>2</sup></b>	Asian	4	2.5
	Black/African	2	1.3
	Latinx	3	1.9
	White	130	81.3
	Multiracial	14	8.8
	Other	6	3.8
<b>Gender<sup>2</sup></b>	Cisgender Man	31	19.4
	Cisgender Woman	85	53.1
	Transgender Man	7	4.4
	Transgender Woman	11	6.9
	Non-Binary	25	15.6
<b>Sexual Orientation<sup>3</sup></b>	Asexual	19	11.9
	Bisexual	31	19.4
	Heterosexual/Straight	60	37.5
	Homosexual/Gay/Lesbian	13	8.1
	Pansexual	7	4.4
	Queer	25	15.6
	Questioning	2	1.3
	Other	1	.6

$n^1 = 160$ ,  $n^2 = 159$ ,  $n^3 = 158$

### C. **Materials**

The EAPS Survey contained 28 items designed to learn key information about the experiences, challenges, and preferences of autistic and neurodivergent postsecondary students. The survey included five sections: demographics and student status, disability identity, past education experiences, current education experiences, and open-ended questions. This study focused on demographics and student status, disability identity, and open-ended questions; demographic questions asked about participants' age, race, gender, and sexual orientation, student status asked about participants' degree status and institutional affiliation, and disability identity asked about preferred terms and language under the neurodivergent umbrella. Open-ended questions inquired into students' experiences, asking the following three questions about facilitators ("positive"), barriers ("challenges"), and resources in postsecondary education:

1. What has been positive about your university experience?
2. What challenges have you faced in your university experience?
3. What resources at your university have you found helpful?

Future studies will explore demographic information and data on past and current education experiences.

### D. **Procedure**

The EAPS Survey was developed to explore autistic and neurodivergent postsecondary students' experiences and piloted by a group of six autistic students, who offered feedback on the questions and language of the survey. Following approval

by the Institutional Review Board (Appendix), the updated online survey was distributed via email and social media. Participants were informed of the purpose of the study and instructed that they could skip any questions they chose not to answer. Participants were not offered any compensation for participating. The survey was available for a period of two months.

#### E. **Data Analysis**

Qualitative data, including the open-ended responses about facilitators, barriers, and resources, were converted to an Excel spreadsheet and analyzed using Braun and Clarke's (2006) six steps to thematic analysis: familiarization with data, coding, generating themes, reviewing themes, labeling themes, and identifying exemplars. Thematic analysis was conducted manually by one coder, the author of this thesis. Due to the length of responses, some responses may have received more than one distinct code. Themes are reported if they occurred in at least 10% of all responses. Quantitative data was analyzed using SPSS to calculate participant demographics.

## IV. RESULTS

### A. **Facilitators**

There were 135 responses to the question on facilitators that could be categorized three themes and seven sub-themes that appeared in at least 10% of all responses. The three themes were identified as opportunities (sub-themes: courses, personal growth, career growth, extra-curriculars), relationships (sub-themes: peers, mentors, communities), and accommodations (Figure 1).

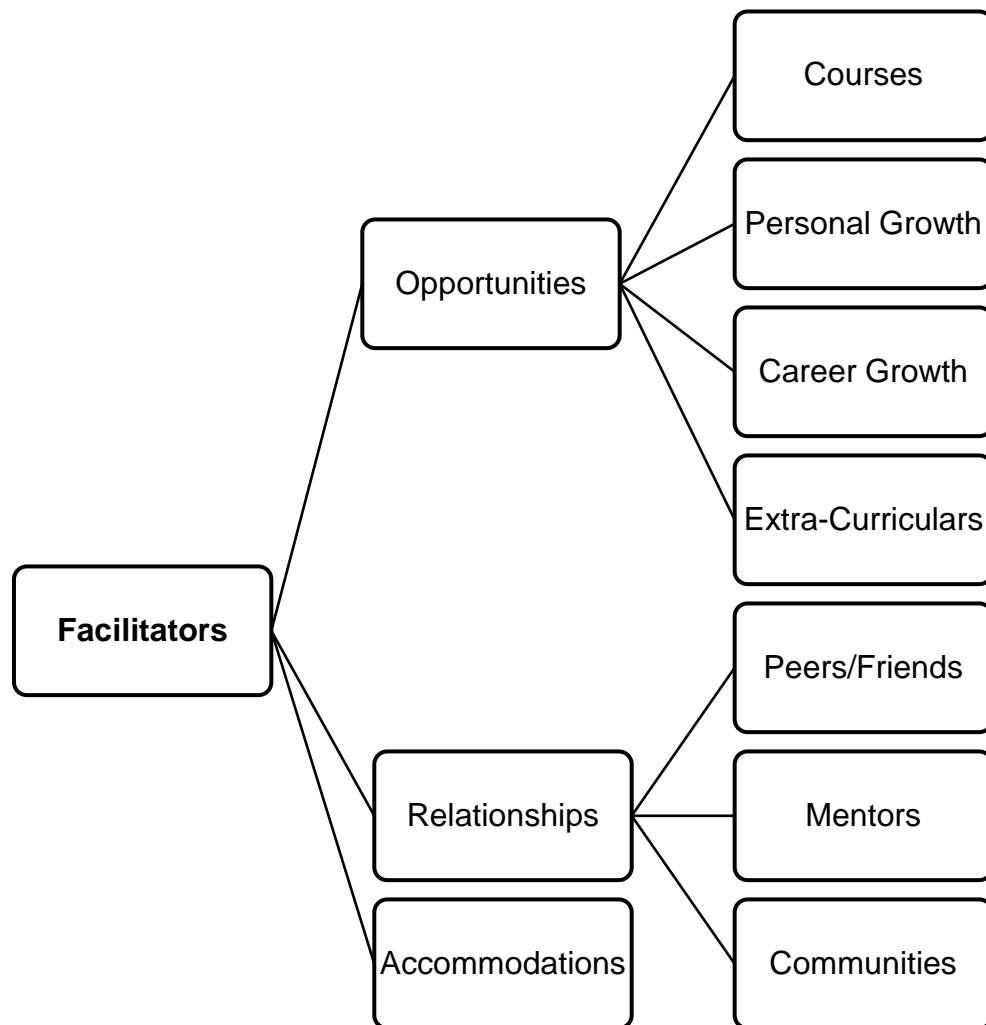


Figure 1. Facilitators themes and sub-themes.

## 1. **Opportunities**

Increased opportunities for learning, growth, and new experiences was a pervasive theme among responses on facilitators for student success and satisfaction. This theme captures participants' excitement at the opportunities afforded to them as college students. The most prominent sub-theme for facilitators was enthusiasm for courses. Participants noted the variety of courses, engaging topics, love of learning, and being able follow their passions when choosing courses:

*I have taken some interesting and fulfilling courses.*

*I truly enjoy the work I do and some of the classes I've taken.*

*I finally get to pursue my passion and take the classes I enjoy.*

*I love learning now.*

Two related sub-themes were personal growth and career growth. Participants noticed changes within themselves and made progress toward their goals. Regarding personal growth and identity, participants remarked:

*... what I am learning about myself and my program are the most valuable things*

*I have experienced.*

*... growing into myself as an individual, coming out as queer and self-actualizing,*

*feeling like I'm doing something that will have value in the future.*

*I have been able to explore my life and myself and develop myself in all aspects of my life.*

Participants also expressed satisfaction at working towards career goals:



*... moving towards my future goals, networking.*

*... taking the next step to a full-time career with all my classes.*

Finally, participants mentioned a range of extra-curricular opportunities including research, travel, and participation in student organizations:

*I like the research project I was hired to do.*

*I've also been able to have experiences I never would have thought possible. I went to New York, New Zealand and traveled Europe through my college. I'm forever grateful for my time in undergrad.*

*I was involved in extracurriculars and made most of my friends from the club tennis team.*

## 2. **Relationships**

The second theme to emerge for facilitators is relationships, including relationships with friends/peers, relationships with professors/advisors/mentors, and relationships with/membership within communities. Participant responses on relationships emphasized the need for support, understanding of disability identity and intersecting identities, and feeling comfortable with certain people or groups. Participants noted the support they received from friends and peers as an improvement from past educational experiences:

*My cohort is aware of my [disability] status and are really supportive in helping me.*

*The people are really nice; there's not a whole lot of drama like in high school.*

*I have several college friends that I expect to keep for life, and I even met my wife volunteering with a community service group.*

Participants also reported the quality of relationships with professors, advisors, and mentors as a facilitator of positive experiences:

*Most of my teachers were decent in my opinion and some were exceptional.*

*My professors made safe and accessible learning environments, and that made me motivated learning more.*

*Having a supportive advisor who lets me excel.*

*I had supportive mentors in both college and grad school.*

Finding community, including specific communities around disability identity and lesbian, gay, bisexual, transgender, and queer (LGBTQ+) identity, was another sub-theme that yielded emphatic responses:

*I have built such a fantastic community in my time here and am so happy to know the people I know. Being a part of communities that support my access needs and respect my existence as a queer, disabled, woman has been life-changing.*

*I get to see other openly Neurodivergent people! Autistic people! People like me!*

*I have been able to form relationships with other people like me and I feel like I am part of a community.*

### 3. **Accommodations**

The final theme for facilitators of positive experiences is accommodations/disability services. Some participants mentioned accommodations

broadly or specific offices and programs intended for disabled, autistic, or neurodivergent students. Other participants elaborated on their experience with accommodations and disability services, specifically the way improved accommodations led to academic success:

*I also receive better support for my disabilities than in high school.*

*The Office of Educational Accessibility was outstanding in making sure I was as successful as I wanted to be.*

*I feel like my achievements as a student are being seen better because I have better access to classes and accommodations.*

*Most university offices care about the access and inclusion of disabled students.*

*We have a great Disability Services office and a full-time ADA coordinator.*

## B. **Barriers**

There were 144 responses to the question on barriers, three themes, and four sub-themes that appeared in at least 10% of all responses. The themes were identified as disability-related barriers (sub-themes: accommodations, discrimination, mental health, executive functioning), socialization, and academics (Figure 2).

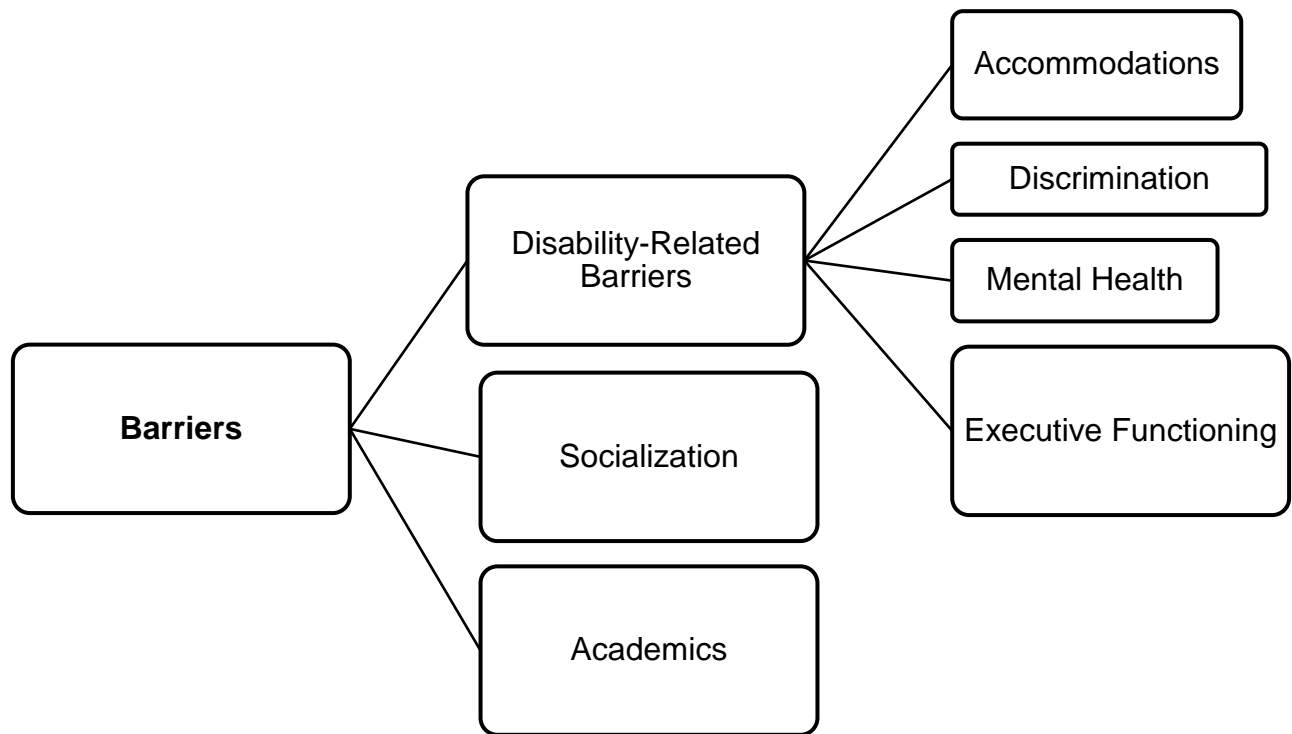


Figure 2. Barriers themes and sub-themes.

# 1. **Disability-related barriers**

Many barriers reported by participants were related to disability/ neurodivergence, though perhaps not as one would expect. The four sub-themes for disability-related barriers are accommodations, discrimination/stigma, mental health, and executive functioning. Participants primarily noted frustration with universities failing to provide or professors refusing to acknowledge accommodations. Regarding accommodations, participants said:

*When I first started as an undergrad, I had to drop out because my university refused to provide adequate accommodations for my learning disabilities.*

*I have faced challenges with my professors adhering to my accommodations.*

*I have to fight with professors every semester to get the accommodations recommended for me. I am constantly told that the accommodations are not fair and give me an advantage over other students.*

Some accommodations barriers, such as professor's ableist attitudes toward accommodations as unfair, connect to the sub-theme of discrimination. Participants noted discrimination from both professors and peers and the alienation such discrimination evoked:

*I faced a lot of overt ableism.*

*There's discrimination from faculty and staff, a general lack of caring about students with disabilities, there's discrimination from students within the program and what I would characterize as a hostile, know-it-all environment and culture from some of the students.*

*... alienating experience as a neurodivergent psych major.*

Perhaps unsurprisingly given such discrimination, the third sub-theme for disability-related barriers is mental health. Participants mentioned depression, anxiety, suicidality, and mental health crises, as well as lack of access to counseling:

*... severe depression, anxiety, and suicidality at times, lack of adequate support from school counseling center and difficulty finding a therapist I could afford in the community.*

*... mental health crisis that is making me consider resigning currently that is a result of overwork and concurrent mental illness.*

*... periods of depression interfere with consistent engagement.*

The fourth and final sub-theme for disability-related barriers is executive functioning issues, which interfered with students' ability to achieve in postsecondary education and contributed to higher levels of stress. Specifically, participants mentioned focus, organization, time management, and motivation as areas of difficulty:

*My ADHD and poor working memory make me take at least twice as long to write something.*

*... attention, focus, organization...*

*... difficulty getting all the work organized and completed on time.*

## 2. **Socialization**

Another theme in responses on barriers was socialization. Participants emphasized trouble making friends, navigating social rules, and experiencing loneliness:

*I have struggled to get involved and make new lasting friendships.*

*I have found it hard to make friends and feel wanted.*

*... navigating academic social rules and making friends.*

*... navigating social dynamics, especially in large situations.*

## 3. **Academics**

The third theme to emerge from responses on barriers is struggling with academics. Participants highlighted specific subject areas or assessments, such as test-taking or writing assignments, and adjusting to new teaching styles and increased course loads:

*I struggle with giving presentations and I can get really nervous about midterm/final papers/assignments.*

*I have a lot of trouble writing essays.*

*I have faced difficulties with adjusting to lecture-based classes.*

*I was completely unequipped to handle the amount of work.*

## C. **Resources**

There were 127 responses to the question on resources, three themes, and three sub-themes that occurred in at least 10% of all responses. There were fewer extensive

comments regarding student resources, which mostly consisted of single word answers (“accommodations”). The themes were identified as accommodations, mental health counseling, and academic student services (sub-themes: tutoring, advising, library services; Figure 3). Participants also listed resources that overlapped with facilitators, including specific relationships and communities.



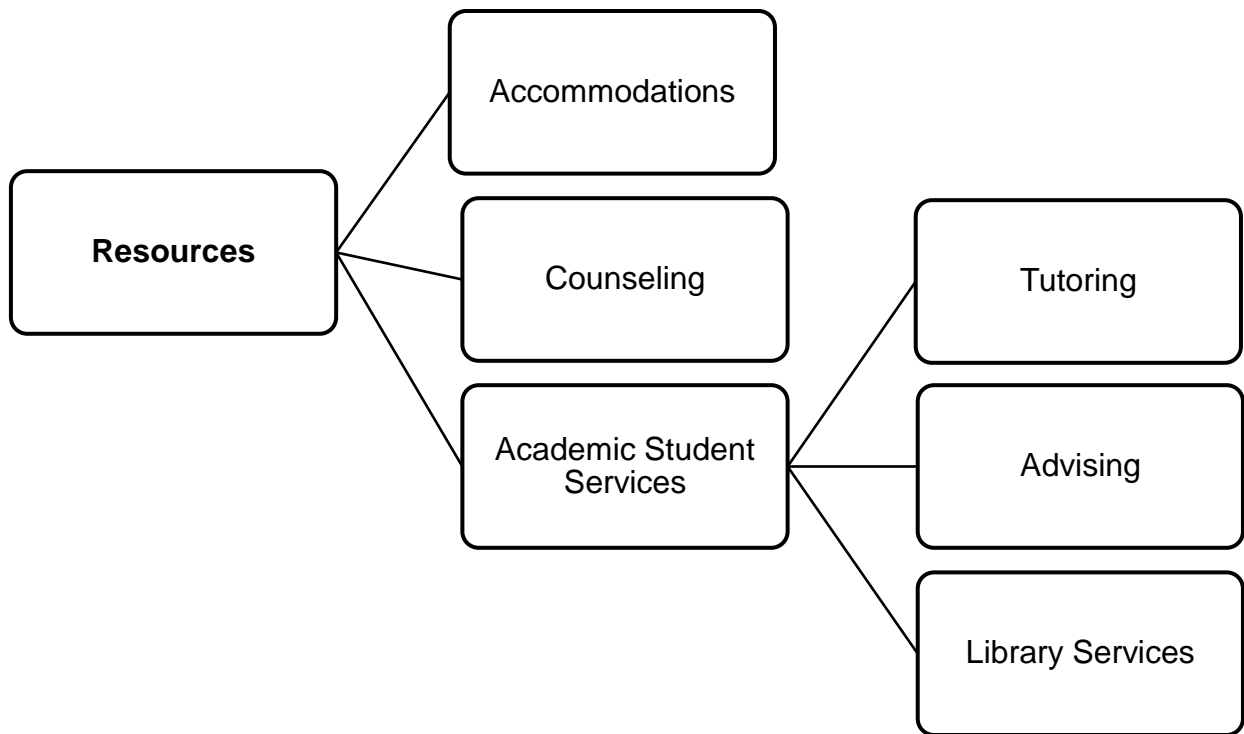


Figure 3. Resources themes and sub-themes.

## 1. **Accommodations**

Students benefited from testing accommodations, attendance accommodations, and assistive technology provided by their college. Over half the participants listed accommodations/disability services as a beneficial resource:

*Accommodations have helped me the most.*

*Accommodations have been immensely helpful and the professors being outwardly willing to accommodate students.*

However, many participants qualified their answer with the recognition that accessing accommodations is itself a challenge:

*Though disability services offices aren't always easy or pleasant to work with, the accommodations do help.*

*We have a testing center that is good if the professor allows tests and quizzes to be taken there. Some refuse to let students use the testing center.*

## 2. **Counseling**

Counseling was another theme that emerged for resources. Nearly a quarter of students stated that university counseling/mental health services were helpful:

*University mental health services were easily accessible, free, and of very high quality.*

*There is counseling for graduate students included in our healthcare, thankfully. ... therapy and self-care.*

Given that mental health emerged as a theme for barriers, it is unsurprising that students benefited from mental health services. Regardless, some participants reported that their disability status made finding suitable mental health care more difficult or noted the inadequacy of campus mental health services in general:

*I tried counseling services and they didn't believe I had autism or ADHD.*

*I tried to go to counseling once, but it took me over 2 months to get an appointment, and after the initial consultation, I was told that they couldn't do anything to help me. Needless to say, I stopped going there.*

*It's very hard to find information about counseling.*

*... campus counseling (though it is not enough).*

### 3. **Academic student services**

Finally, participants cited a range of academic student services as useful resources, including tutoring/academic support services, library services, and academic advising. 10-20% of participants reported the usefulness of various academic student services:

*... student services, tutoring, advising...*

*General Learning Strategies class to teach time management and study techniques.*

*Getting the right advisor has made a huge difference.*

Some participants also noted specific academic tutoring services such as writing centers and accounting or mathematics labs. Notably, participants demonstrated a

preference for mainstream academic support over autism-specific resources such as peer mentoring or academic coaching.

## V. DISCUSSION

### A. Summary

Facilitators of student success and satisfaction included opportunities (sub-themes: courses, personal growth, career growth, and extra-curriculars), relationships (sub-themes: friends, professors/mentors, and communities), and accommodations. Barriers to success and satisfaction included disability-related barriers (sub-themes: accommodations, discrimination, mental health, and executive functioning), socialization, and academic barriers. Participants noted accommodations, mental health counseling, and academic student services as useful resources.

Intriguingly, accommodations were cited as a facilitator, barrier, and resource. This result gestures to the accommodations process as imperfect, yet critical to the success of autistic and neurodivergent students, as well as other students with disabilities. Participants revealed that accommodations allowed them to participate and achieve academically beyond what they had experienced in secondary school. However, participants also noted struggling to get professors and departments to honor their accommodations. Some participants cited professors' claims that accommodations provide students with an "unfair advantage," a common rhetoric used to deny disability services or accommodations. When professors refuse or struggle to provide accommodations, student success and satisfaction suffers. Overall, participants acknowledged the significance and limitations of the current accommodation process.

Among facilitators for student success and satisfaction, opportunities for academic and extra-curricular learning and personal and career growth was the most common theme. In the US, postsecondary education is heralded as a period of identity

development, newfound independence, and self-exploration, making this result unsurprising. College life includes an overwhelming array of elective courses and extra-curricular student organizations, and many of these options promote personal and career growth as well. Autistic and neurodivergent students may also have unusually intense interests in specific topics, and college is an ideal time to explore these topics, passions, or hobbies. Students should be encouraged to engage in the courses and opportunities they find exciting or meaningful, as this can facilitate more positive college experiences.

While difficulty with social interaction was a barrier to positive student experiences, relationships with peers, mentors, and communities was a facilitator. Relationships as a facilitator indicates the importance of close ties and social support, despite atypical social behaviors associated with autism. Some participants indicated that they had an easier time making friends in college than they did in high school, possibly due to interacting with larger pools of peers and improved social skills as they mature. Supportive professors and advisors also contributed to student success and satisfaction. Finally, participants expressed delight at belonging to communities, specifically LGBTQ+ and disability communities, at college. Connecting with other autistic, neurodivergent, disabled, or queer folks is central to social support and identity development for members of these communities.

The results also reveal the wide range of disability-related barriers students face. In addition to accommodations and social struggles, autistic and neurodivergent students reported difficulty with ableism and discrimination, executive dysfunction, and co-occurring mental health issues. Mental health counseling services were also cited as

a resource. Autistic and neurodivergent students face myriad challenges that constitute the autistic/neurodivergent experience. Notably, these challenges arise from the condition and co-occurring conditions and from ableism within academia.

**B. Implications**

Centering autistic and neurodivergent students' perspectives strengthens the research on these students' experiences. My findings largely aligned with previous research on student perspectives. Two new findings to emerge from this research are the critical role of accommodations as both facilitator and barrier and the importance of LGBTQ+ and disability community in college. By better understanding the facilitators and barriers to student success and satisfaction, educators, administrators, and other professionals can better develop initiatives to support these students. Researchers can continue to explore solutions to barriers, and students can embrace the facilitators that promote positive experiences.

**C. Limitations and Recommendations**

My study has two key limitations: survey design and participant sample. An online survey was the best method to solicit responses from numerous participants. However, the qualitative response questions were subject to the participant's interpretation, with no option for clarification. Similarly, researchers were unable to follow up with participants based on their responses for clarity and further information. While the themes identified in the study occurred in at least 10% of all responses, participants are likely to share other common experiences that did not emerge from the questions posed.

Additionally, participants self-selected to participate in the study, and may not be a representative sample. Participants were primarily white, which may have skewed the results to obscure the unique experiences of neurodivergent students of color. Black and Indigenous people and other people of color are underrepresented in autism and neurodiversity research, services, and advocacy due to diagnostic bias towards white individuals, racism within medical and educational contexts, and other factors that contribute to racial injustice and disparities. Participants also self-identified as autistic or neurodivergent, which excludes the perspectives of students who meet criteria for the condition but lack an autistic/neurodivergent identity. Additional research should include more diverse participant samples and compare the experiences of neurodivergent students to neurotypical students.

In addition to further research centering autistic and neurodivergent Black and Indigenous people and other people of color, I offer the following recommendations to continue the work presented here. Future research should investigate and improve the accommodations process to ensure that accommodations are accessible and implemented properly for all students who would benefit from them. Addressing professor's resistance and ableist beliefs about accommodations as an unfair advantage is key to this effort. Future research should also explore autistic and neurodivergent students' level of social support and campus resource utilization, as results indicated students preferred mainstream academic resources over autism-specific services.



#### D. **Conclusion**

The study explored facilitators and barriers to student success and satisfaction as reported by autistic and neurodivergent students attending college in the United States. Facilitators, barriers, and resources were coded using thematic analysis and themes occurring in at least ten percent of all responses were reported. Facilitators included opportunities, relationships, and accommodations. Barriers included disability-related barriers, socialization, and academics. Participants also reported using various campus resources including accommodations/disability services, tutoring and library services, and mental health counseling. The implications of this research are improved understanding of autistic/neurodivergent/disabled student experiences which can be used to improve support initiatives and direct future research.

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## APPENDIX

### Exemption Granted

November 16, 2018

Helen Rottier, BS  
Disability and Human Development

**RE: Research Protocol # 2018-1387**  
**“Experiences of Autistic University Students (EAUS)”**

**Sponsors: None**

**Please be reminded of need to prospectively address institutional approval requirements at the non-UIC Sites** (Columbia College, DePaul University and Roosevelt University).

**This exemption does not include approval for Susan Kahan to conduct the research** as her UIC Investigator Training Period expired on August 30, 2014.

Dear Hellen Rottier:

Your Claim of Exemption was reviewed on November 16, 2018 and it was determined that your research protocol meets the criteria for exemption as defined in the U. S. Department of Health and Human Services Regulations for the Protection of Human Subjects [(45 CFR 46.101(b))]. You may now begin your research.

<b><u>UIC Exemption Period:</u></b>	<b>November 16, 2018 – November 15, 2021</b>
<b>Lead Performance Site:</b>	UIC
<b>Pending Sites:</b>	Columbia College, DePaul University and Roosevelt University
<b>Subject Population:</b>	Adult (18+ years) subjects only
<b>Number of Subjects:</b>	6000

**The specific exemption category under 45 CFR 46.101(b) is: 2**

You are reminded that investigators whose research involving human subjects is determined to be exempt from the federal regulations for the protection of human subjects still have responsibilities for the ethical conduct of the research under state law and UIC policy. Please be aware of the following UIC policies and responsibilities for investigators:

1. Amendments You are responsible for reporting any amendments to your research protocol that may affect the determination of the exemption and may result in your research no longer being eligible for the exemption that has been granted.
2. Record Keeping You are responsible for maintaining a copy all research related records in a secure location in the event future verification is necessary, at a minimum these documents include: the research protocol, the claim of exemption application, all

questionnaires, survey instruments, interview questions and/or data collection instruments associated with this research protocol, recruiting or advertising materials, any consent forms or information sheets given to subjects, or any other pertinent documents.

3. Final Report When you have completed work on your research protocol, you should submit a final report to the Office for Protection of Research Subjects (OPRS).

Please be sure to use your research protocol number (listed above) on any documents or correspondence with the IRB concerning your research protocol.

We wish you the best as you conduct your research. If you have any questions or need further help, please contact me at (312) 355-2908 or the OPRS office at (312) 996-1711.

Sincerely,  
Charles W. Hoehne, B.S., C.I.P.  
Assistant Director, IRB #7  
Office for the Protection of Research Subjects

cc: Tamar Heller



**Exemption Determination  
Amendment to Research Protocol – Exempt Review  
UIC Amendment #1**

January 3, 2019

Helen Rottier, BS  
Disability and Human Development

**RE: Protocol # 2018-1387  
“Experiences of Autistic University Students (EAUS)”**

**This exemption does not include approval for Susan Kahan to conduct the research as her UIC Investigator Training Period expired on August 30, 2014.**

Dear Helen Rottier:

The OPRS staff/members of Institutional Review Board (IRB) #7 have reviewed this amendment to your research, and have determined that your amended research continues to meet the criteria for exemption as defined in the U. S. Department of Health and Human Services Regulations for the Protection of Human Subjects [(45 CFR 46.101(b))].

**The specific exemption category under 45 CFR 46.101(b) is: 2**

You may now implement the amendment in your research.

Please note the following information about your approved amendment:

**Exemption Period:** January 3, 2019 – January 2, 2022

**Amendment Approval Date:** January 3, 2019

**Amendment:**

Summary: UIC Amendment #1: To ensure enough data will be obtained for analysis and due to the cost of distributing the survey via university massmail, the scope of the project has changed from four Chicago-area universities to autistic and neurodivergent university students across the United States. The survey will be distributed via email, Facebook, and Twitter and will be specifically shared by autistic advocates, advocacy organizations, and disability services offices at campuses across the United States. The change in scope has resulted in slight changes to the survey and consent form.

You are reminded that investigators whose research involving human subjects is determined to be exempt from the federal regulations for the protection of human subjects still have responsibilities for the ethical conduct of the research under state law and UIC policy. Please be aware of the following UIC policies and responsibilities for investigators:

1. Amendments You are responsible for reporting any amendments to your research protocol that may affect the determination of the exemption and may result in your research no longer being eligible for the exemption that has been granted.

2. Record Keeping You are responsible for maintaining a copy all research related records in a secure location in the event future verification is necessary, at a minimum these documents include: the research protocol, the claim of exemption application, all questionnaires, survey instruments, interview questions and/or data collection instruments associated with this research protocol, recruiting or advertising materials, any consent forms or information sheets given to subjects, or any other pertinent documents.
3. Final Report When you have completed work on your research protocol, you should submit a final report to the Office for Protection of Research Subjects (OPRS).

Please be sure to use your research protocol number (2018-1387) on any documents or correspondence with the IRB concerning your research protocol.

We wish you the best as you conduct your research. If you have any questions or need further help, please contact me at (312) 355-2908 or the OPRS office at (312) 996-1711.

Sincerely,  
Charles W. Hoehne, B.S., C.I.P.  
Assistant Director, IRB #7  
Office for the Protection of Research Subjects

cc: Tamar Heller

## VITA

**NAME:** Helen Rottier

**EDUCATION:** BS, Psychology, University of Wisconsin-Madison, Madison, Wisconsin, 2018

MS, Disability and Human Development, University of Illinois at Chicago, Chicago, Illinois, 2020

**RESEARCH:** Institute on Disability and Human Development, University of Illinois at Chicago, Chicago, Illinois 2018-2020

Gernsbacher Lab, University of Wisconsin-Madison, Madison, Wisconsin, 2018-2020

**HONORS:** Autistic Self Advocacy Network Autism Campus Inclusion Fellowship, Washington, DC, 2019

Foundation for Science and Disability Student Award, 2019

Illinois Leadership and Education in Neurodevelopmental Disabilities Fellowship, Chicago, Illinois, 2018-2019

**PROFESSIONAL MEMBERSHIP:** Association on Higher Education and Disability  
American Psychological Association

**SELECTED PRESENTATIONS:** Rottier, H. (2020, April). Our existence is resistance: Autistic academics in an anti-autistic academy. In D. Nepveux (Chair), Resistance and resilience across the academy. Session presented at the Society for Disability Studies @ Ohio State University @ Zoom virtual conference.

Heller, T., Buck, A., Izzo, M., & Rottier, H. (2019, November). Cross-center scale-up of the EnvisionIT curriculum: Ohio and Illinois UCEDDs leading change together. Panel presented at the Association of University Centers on Disability Annual Conference, Washington, DC.

Rottier, H. & Guberman, J. (2019, November). Research agenda in and for #ActuallyAutistic online communities. In M. Devito, et al. (Chairs), Social technologies for digital wellbeing among marginalized communities. Workshop presented at the 22nd ACM Conference on Computer-Supported Cooperative Work and Social Computing, Austin, TX.