

**INVESTIGATING HIGHER EDUCATION INSTITUTIONS'
INFLUENCE ON THE EVERYDAY INFORMATION PRACTICES OF
STUDENTS WITH AUTISM**

A Dissertation Presented for the
Doctor of Philosophy
Degree
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Kevin Joseph Mallary
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DEDICATION

I dedicate this work to my grandfather, Eugene Boylston. He provided my parents with needed financial and medical resources to ensure my survival as a premature infant, thus empowering me to achieve academic, social, and personal growth. Grandpa, I miss you daily and hope that I continue making you proud.

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ABSTRACT

Students in higher education are expected to master everyday life, which involves receiving and processing copious information, completing assignments, communicating with professors and peers, planning for their careers, and building life skills (e.g., budgeting finances, managing schedules, securing housing). Autistic students, however, encounter affective, cognitive, technological, and social barriers when engaging in everyday information practices (i.e., seeking, using, and sharing information) to accomplish those tasks. Higher education institutions unaware of or unwilling to accommodate autistic students' wide-ranging information needs may not provide these students with helpful supports. Without having their information needs met, students on the autism spectrum cannot receive the same quality of education as their neurotypical peers.

Referred to as structural agency, scholars should investigate the effects that an institution's people, information, norms, and tools have on consumers' everyday information practices. Research with autistic students has rarely addressed the influence of structural agency on their information practices. Hence, the purpose of this dissertation is to understand – from autistic students' perspectives – how people, information, norms, and tools belonging to higher education institutions enable these learners' mastery of everyday life.

To accomplish this purpose, I employed Grounded Theory Method to investigate the relationship between the structural agency that higher education institutions provide and autistic students' information practices. Taking a user-centered approach, I conducted 16 initial and 13 follow-up interviews with undergraduate and graduate students with autism belonging to two flagship universities in the Southeastern United States. To collect the richest data possible, I invited participants to create everyday life maps, which are illustrations of the people, information, norms, and tools that influence how they balance the academic and everyday demands of higher education. Following multiple rounds of initial, axial, and theoretical coding of participants' transcripts and maps, I

found that (a) structural agency, (b) personal support systems, (c) everyday information practices, (d) optimal functioning, and (e) belonging collectively contribute to autistic students' sensory and social well-being. To conclude, I propose and apply a theoretical model of sensory and social well-being and recommend actionable strategies that professors and staff members can implement to enhance students' sensory and social well-being.

Keywords: Everyday information practices, structural agency, sensory well-being, social well-being, autism spectrum disorder, library and information services, higher education

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CHAPTER ONE: INTRODUCTION

Norman, a second-year student at The University of Tennessee at Chattanooga (UTC), is on the autism spectrum (West, 2019). Autistic students can exhibit various deficits in communication and socialization, along with restricted, repetitive patterns of behavior, interests, or activities (e.g., cognitive inflexibility, sustaining interest) (American Psychiatric Association, 2013). To mitigate the influences these behaviors had on his learning during high school, Norman depended on his mother for help communicating with others and completing schoolwork. Now a college student, Norman participates in an autism support program provided by his institution. This specialized program pairs students on the autism spectrum with their neurotypical peers, who help locate, use, and share information for accomplishing academic and everyday tasks. Norman has greater autonomy by participating in this program because he no longer depends solely on his mother to support his educational and daily concerns. Although autism support programs such as UTC's have proven beneficial for autistic students and their families, these programs can be costly (i.e., \$3,500.00–7,500.00 aside from tuition costs), making them inaccessible to many students who need them.

Alongside their neurotypical peers, students with autism navigate the rigors of higher education to receive an education and achieve personal and social growth (Campbell et al., 2018). Inside and outside classrooms, students are expected to receive and process copious information, complete assignments, communicate with their professors and peers, plan for their careers, and build life skills (e.g., budgeting finances, managing schedules) (Head & Eisenberg, 2011). Generally, being unable to balance academic and everyday demands can yield uncertainty for students (Given, 2002).

Students' everyday lives dictate the information they need (Hertzum & Hyldegard, 2019). Information needs include building topical knowledge (Thomas et al., 2017), comprehending professors' expectations (Head, 2013), confidently

completing assignments (Ross et al., 2016), studying for examinations (Given, 2002), researching careers (Sin & Kim, 2013), and securing housing (Sirgy et al., 2007). Reducing anxiety (Sprung & Rogers, 2021), achieving autonomy (Potnis & Mallery, Forthcoming), and learning how to communicate competently (Bartlett et al., 2020) are additional concerns reported by students.

To satisfy their information needs, students employ everyday information practices (i.e., locating, utilizing, and exchanging information) (Savolainen, 2008). For example, students browse electronic resources (e.g., academic library databases, electronic books, Google Scholar, Wikipedia) (Weber et al., 2019); consult their professors, peers, and relatives for assistance locating information (Murphy, 2014); evaluate the credibility of information (Weiler, 2005); apply knowledge for completing assignments (Lupton, 2008); and utilize mobile devices and social networking platforms to share knowledge with their peers (Eid & Al-Jabri, 2016; Mills et al., 2014).

Problem Statement

Students with autism encounter numerous affective, cognitive, technological, and social barriers when searching for, using, and sharing information. Affective and cognitive barriers which can shape autistic students' information practices include their perceived uncertainty (Getzel et al., 2019) and cognitive inflexibility (Anderson et al., 2019). Difficulty using searching interfaces (Williams & Hennig, 2015), and the presence of inaccessible electronic resources (Beyene, 2019), are technological barriers. Finally, social barriers could involve students' inappropriate communicative behaviors (McKeon et al., 2013) and some professors' unawareness of and unwillingness to implement academic accommodations (Heck-Sorter, 2012). Higher education institutions unaware of or unwilling to accommodate these students' wide-ranging information needs may not provide them with the most helpful supports (Clouder et al., 2020; Nachman, 2020; Shea et al., 2019).

Purpose and Significance

Higher education institutions, such as the two universities represented in this study, “. . . provide stimulus, guidelines, and resources for acting as well as prohibitions and constraints on action” (Scott, 2014, p. 54). Learners who feel supported by their institutions are likely to achieve academic and personal growth, whereas those who lack needed information and tools may underperform expectations (Tinto, 2012). Referred to as structural agency, scholars should investigate the enabling and constraining effects of an institution’s people, information, norms, and tools on consumers’ everyday information practices (Irvine-Smith, 2017). Prior studies of structural agency have privileged providers’ perspectives (e.g., disability support services, librarians, professors) and seldom elicited autistic students’ information needs, leaving these learners without the same quality education as their neurotypical peers (Chapter Two). Hence, this dissertation aims to understand – from autistic students’ perspectives – how higher education institutions can enable these learners’ information practices so they can master everyday life.

To accomplish the study’s purpose, I employed Grounded Theory Method to investigate the relationship between structural agency and the everyday information practices of this marginalized population (Chapter Three). As shared in Chapter Four, (a) structural agency, (b) personal support systems, (c) everyday information practices, (d) optimal functioning, and (e) belonging collectively influence autistic students’ sensory and social well-being. Finally, in Chapter Five, I propose and apply a sensory and social well-being theoretical model. Also, I inform practice in higher education by recommending actionable strategies that professors and staff members can implement to enrich students’ sensory and social well-being.

CHAPTER TWO: LITERATURE REVIEW

Chapter Two, divided into four sections, lays the groundwork for studying the role of structural agency in autistic students' everyday information practices. The first section describes the information needs of students in higher education. Second, the information practices in which neurotypical students engage to balance academic and everyday demands are shared. Third, I discuss how barriers and resources influence the everyday life of students with autism, and I articulate the need for studying this population. Finally, I articulate the theoretical framework guiding the study. The overarching and secondary research questions guiding this study are posed after the review.

Students' Everyday Life

Learners in higher education navigate the rigors of everyday life not simply to receive an education but to achieve personal and social growth (Campbell et al., 2018). My conception of everyday life extends Savolainen's (1995) *way of life*, which holds that people must learn to fulfill their work-related and personal obligations. Accordingly, students are expected to receive and process copious information, complete assignments, communicate with their professors and peers, plan for their careers, and build life skills (e.g., budgeting finances, managing schedules) (Meyer et al., 2014). Being unable to master everyday life can generate uncertainty for students (Given, 2002).

Students' ability to manage their priorities, and excel academically and personally, is primarily influenced by their environment, which is comprised of an institution's attitudes toward students, personnel, instructional practices (e.g., lectures, required readings, and standardized assessments), and values (Rose, 2016). Learners who operate within a supportive environment are likely to achieve academic and personal growth, whereas those who lack needed information and resources may underperform expectations (Tinto, 2012). Hence, students lacking necessary supports exhibit increased uncertainty (Sprung & Rogers, 2021).

Everyday life dictates the information students need to solve problems (Hertzum & Hyldegard, 2019). Wilson (1997) writes that information needs stem from someone's affective (e.g., anxiety, uncertainty) and cognitive (e.g., motivation, knowledge) states. For students, information needs include building topical knowledge (Thomas et al., 2017), comprehending professors' expectations (Head, 2013), confidently completing assignments (Ross et al., 2016), studying for examinations (Given, 2002), researching careers (Sin & Kim, 2013), and securing housing (Sirgy et al., 2007). Reducing anxiety (Sprung & Rogers, 2021), achieving autonomy (Potnis & Mallary, Forthcoming), and learning to communicate more competently (Bartlett et al., 2020) are additional concerns reported by students. Students capable of solving problems and satisfying their information needs could effectively balance the academic and everyday demands of higher education (Martin & Marsh, 2008).

Students' Information Practices for Mastering Everyday Life

"As we learn through our encounters with information, as we seek out information, work with information, and give others the benefit of our learning, we are engaged in important learning processes in today's information and knowledge contexts" (Bruce, 2008, p. 15). Collectively referred to as information practices, searching for and using needed information and exchanging that knowledge with others is fundamental to mastering everyday life (Savolainen, 2008). Hence, within higher education, students must search for and use information, and share their knowledge with others to master everyday life.

Information-Seeking

Defined as the active search for information, information-seeking is a collection of behaviors that stem from an information-seeker's desire for knowledge (Case & Given, 2016). To obtain knowledge, people employ various information-seeking strategies: purposefully searching for information (Wilson, 2016), passively receiving information (Savolainen, 2005), incidentally acquiring information (Williamson, 1998), and obtaining information via proxy information-seeking (i.e., acquiring knowledge through a third-party) (McKenzie, 2003).

Students in higher education, like the participants in this study, engage in similar information-seeking behaviors.

Searching for needed information can help reduce students' uncertainty (Kuhlthau, 2004). Google and Wikipedia (Selwyn & Gorard, 2016), along with academic library databases, electronic books, and Google Scholar, are valuable resources for satisfying students' academic information needs (Weber et al., 2019). Students may even utilize those resources to address their everyday concerns, such as researching careers, establishing, and maintaining relationships, and making health-related decisions (Sin & Kim, 2013). However, students' limited awareness of print and digital resources may preclude them from locating useful information (Head, 2013). Being unaware of valuable resources (Hertzum & Hyldegard, 2019) and unable to structure keywords effectively (Bilal & Kirby, 2002) contribute to students' uncertainty.

If students struggle to find needed information, they seldom consult academic librarians (Callinan, 2005). Instead, these students often solicit information from their professors, peers, and relatives since these people are perceived to be accessible and trustworthy sources (Murphy, 2014). Some students may even receive unsolicited information, which could be helpful (Given, 2002). With this information, students attempt more relevant searches (Bronstein, 2014). Thus, students' relationships are instrumental in seeking information (Head & Eisenberg, 2011).

When determining whether to use the information for solving problems, students must assess its credibility (Weiler, 2005). For students, believing information can be problematic, especially if the information they find is limited, of questionable authority, conflicts with other information, or is outdated (Sin & Kim, 2013). Rieh and Hilligoss (2008) found that students likely perceive information to be reliable if trusted people (e.g., professors, relatives, peers) attest to its credibility, or the students deem that information useful for solving problems.

Information Use

Once an information seeker has collected needed information, the individual can then use the information for some purpose. Savolainen (2008) describes information use, the second element of information practices, as iterative. People construct meaning from newly discovered information, compare it with existing knowledge, and integrate it into their knowledge base. Referencing Dervin's (2003) Sense-Making Methodology, Fleming-May (2008) articulated that a user's need for information, the perceived ambiguity of a problem, and the applicability of information for solving that problem, jointly influence how information bridges gaps in knowledge.

To bridge gaps in their knowledge, students learn from processing (e.g., annotating, highlighting, synthesizing) and integrating the information being received (Kari, 2010; Maybee, 2006). Then, they apply the skills they have learned to complete academic and everyday tasks (Head & Eisenberg, 2011; Lupton, 2008). Students' use of information is facilitated by various technologies (Cavanaugh et al., 2016). Navigating their learning management systems for meeting deadlines, using digital resources (e.g., electronic books) provided by their academic libraries to flexibly complete their assignments, streaming podcasts and videos, browsing the Internet for news stories, consuming recorded lectures for bolstering their comprehension of academic materials, utilizing spell-checking functions within word-processing applications for generating written assignments, and exchanging academic and everyday information with their peers via social networking and file-sharing platforms (e.g., Facebook, Google Docs, wikis), are all means by which students use information (Henderson et al., 2017; Sin & Kim, 2013).

Information-Sharing

Information practices are inherently social, meaning that people search for and use information, and exchange knowledge, within information grounds (i.e., physical, and virtual places in which people seek, use, and share information) (Fisher et al., 2004). Moreover, information-sharing satisfies various objectives:

managing day-to-day problems, such as medical conditions (Lloyd et al., 2014); sharing expertise with colleagues (Olsson, 2016); and cultivating friendships (Kimm & Boase, 2019). This social dimension distinguishes information practices from information behavior (i.e., people's location and use of information to satisfy their information needs) (Case & Given, 2016). Since knowledge exchange is essential to learning, understanding students' information practices is worthwhile (Given, 2002).

Information-sharing among students occurs when peers exchange books and notes, schedule entertainment activities, aid with locating electronic resources, maintain relationships and study for examinations together (Sin & Kim, 2013; Thomas et al., 2017; Wei et al., 2012). Information is shared in classrooms, hallways, dormitories, coffee shops, and online spaces (Head & Eisenberg, 2011). Like searching for and using information, technologies facilitate students' sharing of information. To satisfy their information needs, students use mobile devices (Mills et al., 2014) and various social networking and file-sharing platforms (e.g., Dropbox, Facebook, WhatsApp, YouTube) (Eid & Al-Jabri, 2016) when exchanging information with their peers.

Autistic Students' Everyday Life

Compared to their neurotypical peers, autistic students attending a higher education institution, the focus of this dissertation, may struggle to master everyday life (Trevisan & Birmingham, 2016).

Barriers Influencing Autistic Students' Everyday Life

Consistent with a predicament model of autism (Anderson-Chavarria, 2021), various affective, cognitive, technological, and social barriers can influence autistic students' information needs and resulting information practices (Table 1).

Affective and Cognitive Barriers. Scholars have found that the information practices of students with autism can be affected by affective and cognitive barriers, such as perceived uncertainty, cognitive inflexibility, and difficulty comprehending scholarly publications and synthesizing information. These barriers affect how autistic students seek, use, and share information.

Perceived Uncertainty. For students in higher education, seeking information can prompt uncertainty (Goldman et al., 2017). Since autistic students possess limited tolerance for uncertainty (Jenkinson et al., 2020), they must be self-efficacious (Getzel et al., 2019). Self-efficacy refers to a student's belief in their ability to accomplish an intended task (Schunk & Mullen, 2012). Dimensions of self-efficacy include (a) the apparent difficulty of an intended task, (b) the general or specific domains in which a learner senses confidence, and (c) the strength of the student's confidence in completing the task (Bandura, 1997). Ross et al. (2016) concluded that students' ability to search for and use the information and share their knowledge requires self-efficacy.

Using participant viewpoint ethnography, Everhart and Escobar (2018) studied a student with autism and a neurotypical peer as they navigated their academic library. The autistic student was confused by call numbers for locating resources and required explicit directions throughout the library (i.e., wayfinding). Although they might benefit from guidance when searching for information, students on the autism spectrum who fear being misunderstood may avoid requesting help from academic librarians more often than neurotypical students (Cho, 2018). Misunderstanding professors' expectations for assignments can exacerbate uncertainty (Fabri et al., 2020). Academic librarians unaware of autistic students' information needs may be ill-prepared to provide the assistance needed to reduce their uncertainty (Layden et al., 2021).

Cognitive Inflexibility. Cognitive inflexibility, which includes information and sensory overload and mind-blindness, may factor into autistic students' everyday information practices. For example, Anderson's (2018) review of online discussion posts found that some students with autism experience information overload when searching for materials needed to complete their assignments. Even organizing the information and tasks that comprise their projects can exacerbate anxiety (Gurbuz et al., 2019).

Sensory overload is another concern for students on the autism spectrum. Students who find their living and study spaces crowded and distracting may struggle to process information (Everhart & Anderson, 2020). On the contrary, for some autistic students, even silence can provoke anxiety (Muir et al., 2009). Although professors may combine multiple stimuli in the classroom to aid information-processing (e.g., lecture slides, videos), these learners have reported anxiety when using multiple senses (Griful-Freixenet et al., 2017). Parents of students with autism have echoed this finding (Hillier et al., 2021).

Aside from information and sensory overload, autistic students may have difficulty sharing information with neurotypical peers. Being unable to understand, predict, and respond to another person's thoughts, actions, and feelings – a phenomenon known as mind-blindness (Baron-Cohen, 1997) – impedes autistic students' communication. Traits of mind-blindness include a delayed theory of mind, an inability to self-reflect, a lack of perspective-taking, and exhibiting inappropriate behaviors (e.g., speaking off-topic, asking inappropriate questions, making limited eye contact) (Clouder et al., 2020). Because of these barriers, some neurotypical students perceive their autistic peers as incapable of contributing to discussions and collaborating on assignments (Underhill et al., 2019), possibly leaving students on the autism spectrum with unsatisfied information needs.

Difficulty Comprehending Readings and Synthesizing Information.

Autistic students' use of information may be impeded if they have difficulty comprehending readings (Carnahan & Williamson, 2019). When processing information contained in scholarly resources, students on the autism spectrum may prefer consuming YouTube videos instead of reading because understanding specialized jargon when learning complex subjects (e.g., medicine, psychology) can hinder materials' readability (Gibson & Hanson-Baldauf, 2018).

Synthesizing information from academic and everyday sources can also impede these learners' application of that information. For example, synthesizing information involves identifying similarities and forming abstract concepts from various ideas (Jordan, 2019). An autistic student, however, may have difficulty assembling individual details and generalizing their thoughts into a single, coherent perception (Gobbo & Shmulsky, 2014). Problems synthesizing information could hinder how students with autism build knowledge and skills for solving problems they encounter in everyday life.

Technological Barriers. In addition to affective and cognitive barriers, technological barriers may also influence mastery of everyday life for students with autism. Technological barriers include autistic students' perceived difficulty using searching interfaces and the presence of inaccessible electronic resources. Some autistic students' inability to navigate searching interfaces (e.g., digital libraries, search engines) effectively and efficiently may prevent them from retrieving needed information (Williams & Hennig, 2015). The presence of inaccessible electronic resources, such as scanned documents that users cannot manipulate, can limit processing of information (Beyene, 2019). Visually complex Web pages (Eraslan et al., 2020), and unintuitive mobile interfaces (Rezae et al., 2020), may impede autistic users' synthesis of available information and their ability to distinguish vital information from extraneous stimuli.

Table 1. Affective, Cognitive, Technological, and Social Barriers Influencing Autistic Students' Everyday life

Barrier Type	Barriers	Seek	Use	Share
Affective and Cognitive	Perceived Uncertainty	X	X	X
	Cognitive Inflexibility	X	X	X
	Comprehending Readings		X	
	Synthesizing Information		X	
Technological	Using Searching Interfaces	X		
	Inaccessible Electronic Resources	X	X	
Social	Inappropriate Communication			X
	Perceptions of Accommodations	X	X	X

Social Barriers. Social is the third collection of barriers that might influence the information practices of students with autism. Autistic students' inappropriate communicative behaviors and some professors' unwillingness to implement mandatory accommodations are social barriers. Speaking off-topic, asking inappropriate questions, and making limited eye contact, are some communicative behaviors that can hinder the exchange of information with professors and neurotypical peers in academic and everyday settings (McKeon et al., 2013; Trevisan & Birmingham, 2016). Although federal laws (e.g., Rehabilitation Act, Americans with Disabilities Act [ADA]) mandate accommodations such as classroom facilitators and assistive technologies, students on the autism spectrum have shared that professors sometimes view them as disadvantageous to neurotypical students and refuse to implement them, thus presenting additional barriers when searching for, using, and sharing information (Sarrett, 2018). Feeling overlooked and socially isolated from other community members can exacerbate anxiety and, for some students with autism, lead to severe depression (Jackson et al., 2018). Given these social barriers, autistic students may decide not to disclose their information needs to authority figures or peers (Thompson-Hodgetts et al., 2020). Consequently, they may not receive adequate supports for satisfying their information needs.

Technological and Social Resources for Supporting Autistic Students'
Everyday Information Practices

Technological and social resources can aid autistic students' information practices. Mobile devices and assistive technologies are technological resources designed to facilitate seeking, using, and sharing of information. For example, note-taking, spell-checking, and Internet browsers (e.g., Google, Siri), are popular mobile applications employed by students with autism (Abbott, 2018). Assistive technologies refer to hardware and software specifically designed to help disabled students, including those with autism, seek, use, and share information in various contexts (Potnis & Mallery, 2021).

Assistive technologies for autistic students include captioning and transcription services, document magnifiers, e-books, dictation software, screen-readers, spell-checking programs, and augmented communication devices (Ahmad, 2015). In addition, adaptive keyboards (Ashby & Causton-Theoharis, 2012), interactive whiteboards (Odom et al., 2015), Smart pens (Abbott, 2018), visual activity scheduling (Spriggs et al., 2015), wearable devices (Williams & Gilbert, 2020), and virtual reality experiences (Grynszpan et al., 2014), are other tools. These hardware and software can enable the location, use, and sharing of information across modalities.

Social resources include disability support services, peers, academic librarians, and perhaps parents. Disability support services can facilitate autistic students' use and sharing of information (VanBergeijk et al., 2008). For example, a specialized accommodation provided by disability support services, classroom facilitators may help students on the autism spectrum comprehend readings, transcribe notes, and share their ideas aloud (O'Neill et al., 2012). In addition, learners can solicit clarification of tasks and expectations for assignments from their neurotypical peers (Singh et al., 2020). Aside from enlisting the support of their peers, students with autism could also receive guidance with searching for and using information (e.g., information literacy instruction, research assistance) from academic librarians. However, their librarians are seldom consulted (Cho, 2018). Along with disability support services, peers, and academic librarians, Carmona-Serrano et al. (2021) suggest that some autistic students' parents may support their children as they navigate the rigors of higher education.

Studies addressing technological and social resources that might aid autistic students' information practices are often conducted with professors, neurotypical peers, disability support services, and academic librarians (Cox et al., 2020). Additional scholarship, however, is needed to understand – from the perspectives of students with autism – how their institutions can afford them structural agency best (Anderson et al., 2019; Berget & MacFarlane, 2020; Everhart & Anderson, 2020). Moreover, if professors and staff members are

unaware of their information needs or perhaps unwilling to assist, they may not receive the supports needed to master everyday life (Clouder et al., 2020; Nachman, 2020; Shea et al., 2019). Given the lack of research with autistic students, I aim to make a user-centered contribution with this study's findings.

Theoretical Lens

Approaches To Studying People's Everyday Information Practices

Scholars have adopted various approaches to investigate people's everyday information practices (Irvine-Smith, 2017). For example, conceptualizations of information practices include (a) people's routine, everyday activities (Pilerot et al., 2017); (b) understandings shared within communities (Olsson, 2016); (c) discursive tools, such as language (Gibson & Martin, 2019); (d) embodied practices (Lloyd & Olsson, 2019); and (e) materialistic and object-driven activities (Huvila, 2018).

Activity Approach. "Family, authority, institutions, and organizations are all kept in existence through the recurrent performance of material activities, and to a large extent, they only exist as long as those activities are performed" (Nicolini, 2012, p. 3). People's activities include their situations, the tasks completed, and the information practices utilized to solve everyday problems (Talja & Nyce, 2015). In addition, cultural artifacts and tools (e.g., histories, languages, technologies) mediate people's daily activities (Engestrom, 2014). Furthermore, Zhao et al. (2020) argue that technologies are ingrained in people's day-to-day activities and enable them to engage in their information practices. Hence, hardware and software (e.g., computers, databases, technical documentation) aid people's resolution of everyday problems (Bystrom & Lloyd, 2012) and the creation of knowledge (Roos, 2012). Ultimately, people's information practices aim to sustain their institutions, which they can accomplish through their routine activities (Pilerot et al., 2017). This dissertation investigates how academic institutions enable the everyday activities of students on the autism spectrum.

Community Approach. People's everyday information practices are also grounded in their communities (Irvine-Smith, 2017). Per a community approach, mastery of everyday life requires that people participate in communities of practice. First, new members learn the expectations, norms, and policies governing their communities from experienced members (Wenger, 1998). Subsequently, people's knowledge and skills acquired from more experienced peers can inform their practices (Olsson, 2016). Hence, people engage in their everyday information practices based on the cognitive authority of others (Ma & Stahl, 2017). As a result, people gradually transform their shared information practices (Mansour, 2020). The learning community in which autistic students participate was explored in this dissertation.

Discursive Approach. The discursive approach to studying people's everyday information practices otherwise referred to as critical discourse analysis, requires understanding how people's identities, languages, and social positions, influence their access to knowledge and the dynamics of power within their institutions (Foucault, 2010). People's everyday information practices are thus shaped by their information access and social connectedness (Olsson & Lloyd, 2017). For example, people who possess authority are information gatekeepers; conversely, people may experience *information marginalization* if they perceive that knowledge is intentionally withheld (Gibson & Martin, 2019). Without sufficient knowledge, autistic students in this dissertation may not receive the same quality education as their neurotypical peers.

Embodiment Approach. People's everyday information practices are further conceptualized as embodied, which must be accounted for in practice research (Pilerot et al., 2017). Per the embodiment perspective, people exchange knowledge and build skills while engaging in shared sensory experiences (Lloyd & Olsson, 2019). Sensory experiences include what people hear, see, and touch (Olsson & Lloyd, 2017). This dissertation examines the information practices of students on the autism spectrum, some of whom encounter sensory barriers, so embodiment is of particular concern.

Materiality Approach. Materials, including cultural objects, technologies, and other tools, shape everyday information practices (Huvila, 2018). “The accomplishment of a practice is, in fact, always attained thanks to both the mastery of skilled, human, embodied actors and the active contribution of a variety of tools . . .” (Nicolini, 2012, p. 223). Within the context of autistic students’ everyday life, classroom objects (e.g., desks, board, lectern), dictate the roles people enact (e.g., instructor, students) and how those actors’ everyday information practices unfold.

Adopting Structural Agency

Another approach to studying people’s information practices is structural agency (Irvine-Smith, 2017). Structures, such as the universities examined in this dissertation, “. . . provide stimulus, guidelines, and resources for acting as well as prohibitions and constraints on action” (Scott, 2014, p. 54). For example, by providing information and tools (e.g., technologies, accommodations) to its stakeholders, an organization enables consumers to engage in routine activities (Nicolini, 2012). Based on my literature review, the information, and tools that enhance autistic students’ information practices include academic accommodations, accessible learning materials, assistive technologies, classroom objects, library collections, and instructional technologies. The information and tools were investigated in this dissertation.

Contrary to supporting stakeholders’ activities, an organization’s norms can constrain people’s everyday information practices (Veinot, 2007). For example, federal regulations, codes of conduct, and instructors’ attendance and grading policies are privileged ways academic institutions, like the ones involved in this study, constrain students’ information practices (Timmermans, 2014).

Aside from information and norms, studies of structural agency should also include the people who comprise the institution (Bourdieu, 1993). Within the context of my research, students on the autism spectrum interact with instructors, peers, relatives, and others (Sarrett, 2018). These people occupy positions of authority and influence the flow and use of information among learners.

As evidenced by the literature review, there are numerous agentic concerns (e.g., executive functioning, communication, socialization) with students on the autism spectrum. Hence, this dissertation seeks to understand how a university can enable or impede these learners' everyday information practices (Figure 1). For example, suppose the institution provides necessary supports to autistic students. In that case, I expect these learners could more readily balance academic and everyday demands.

Research Question

Based on reviewed studies of autistic students' information practices and the need for additional user-centered investigations, this dissertation addresses the following research question: *How can a higher education institution provide structural agency to autistic students engaged in their everyday information practices?* Secondary questions include:

- *RQ(a): What are autistic students' agentic concerns?*
- *RQ(b): What are autistic students' resulting information practices?*

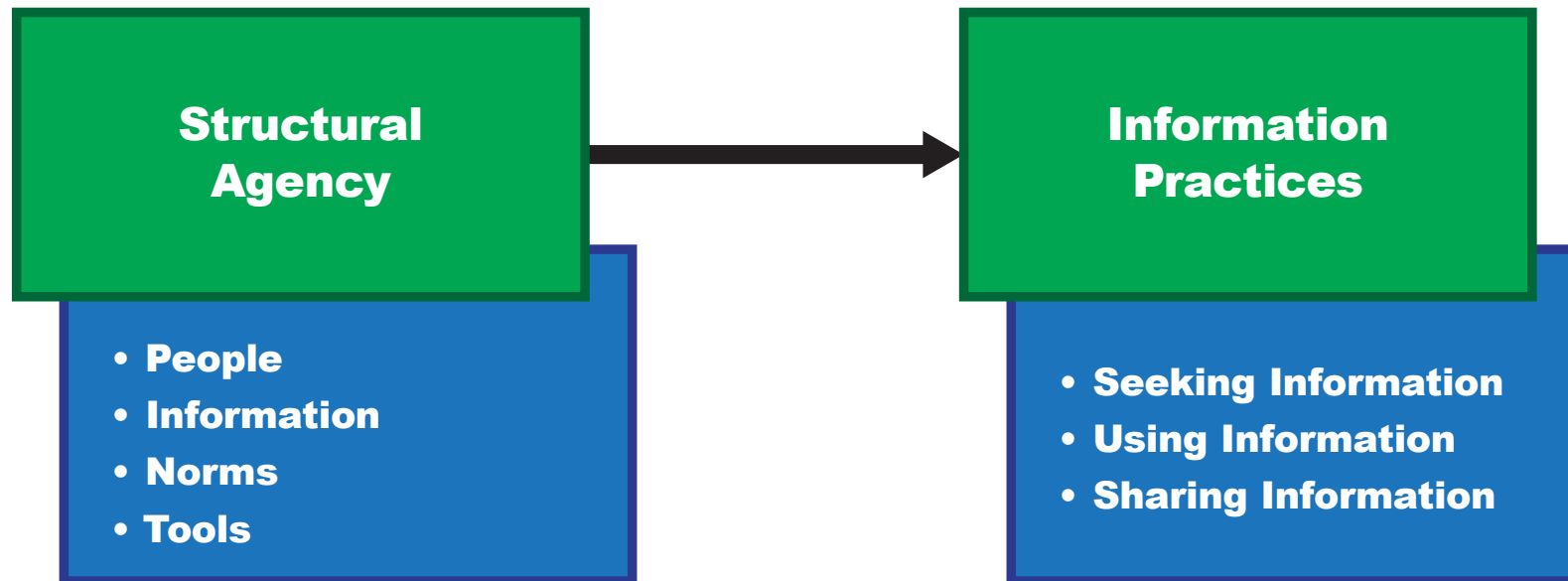


Figure 1. Structural Agency and Information Practices

CHAPTER THREE: METHODOLOGY

Chapter Three describes the methodology used in this dissertation. In the first section, I discuss the Grounded Theory Method. Second, I describe the participants, including the inclusion criteria and recruitment procedure I used. Third, I detail the data collection process, which involved conducting initial and follow-up interviews with participants and collecting everyday life maps. Fourth, I share the data analysis process, including the multiple initial, axial, and theoretical coding rounds. Finally, I discuss the ethical considerations when conducting this research and how I ensured the findings were most rigorous.

Grounded Theory Method

This study is grounded in social constructionism, which sees knowledge as constructed by and shared among community members (Burr, 2015). Because the relationship between structural agency and people's everyday information practices has seldom been examined, I took a grounded theory approach to understand this association better (Creswell & Creswell, 2017). Grounded theory, otherwise known as Grounded Theory Method (GTM) (Morse et al., 2016), helps extract meaning through the rigorous, ongoing collection and evaluation of data. Contrary to the goal of positivist researchers, which is to test or refine existing theory, the objective of scholars who use GTM is to build ideas that explain events within contexts (Charmaz, 2014). GTM is particularly useful for investigating the information practices of marginalized populations (Caidi et al., 2010; Chengalur-Smith et al., 2021; Greyson, 2016), such as the participants in this study. Accordingly, as I collected and analyzed data from autistic students, I developed a theoretical understanding of the role of structural agency (e.g., people, information, norms, tools) in shaping their everyday information practices (Figure 1).

Participants

Inclusion Criteria

This study employed purposive sampling by inviting undergraduate and graduate students who identify as having autistic disorder to participate. Since students on the autism spectrum differ in communicating and learning (Autism Speaks, 2022), obtaining a sizable sample was critical. Therefore, I recruited from two flagships, comparably sized universities in the Southeastern United States, to acquire a sufficient sample.

Recruitment Procedure

Before collecting data, I applied for Institutional Review Board (IRB) approval. Once I received permission to conduct research (Appendix A), I sent an IRB-approved recruitment email message (Appendix B) to both institutions' directors of disability support services. They then forwarded the email message to undergraduate and graduate students with autism currently enrolled in their institutions. Recruiting participants through the directors guaranteed their privacy since I did not know their identities.

Students who wished to participate completed an IRB-approved consent form (Appendix C). The participants' informed consent document was simple regarding its structure and language to improve its readability (Gibson & Hanson-Baldauf, 2018). To verify that a participant (a) is on the autism spectrum; (b) does not have a cognitive impairment that limits their ability to consent ethically; and (c) does not have a legal guardian or representative responsible for making financial, legal, or medical decisions, I included several questions in the body of the form:

- Are you on the autism spectrum?
 - Yes
 - No
- Based on what you have read, select each of the following true statements:
 - I can leave this study anytime without penalty [True]

- There is zero risk to participating in this research [False]
- The researchers will do their best to protect my privacy [True]
- My information will be kept for future research [True]
- Do you have a legal guardian or representative responsible for making financial, legal, or medical decisions on your behalf (e.g., conservatorship, power of attorney)?
 - Yes
 - No

To be eligible for participation, students correctly responded to all three questions (i.e., be autistic, correctly answer the set of statements, and not have a legal guardian or representative). Students who agreed were then asked demographic items (e.g., year in school, major, accommodations received) (Appendix D). Each eligible participant was invited to schedule a convenient time and location – in-person, virtually, or by phone – for the first of two interviews. Participants also requested accommodations they needed to complete the interviews comfortably. I confidentially planned for accommodations with disability support services before the first interview.

Data Collection

Initial Interviews

For collecting data from participants, I utilized semi-structured interviews, which included prepared questions and left open the possibility of follow-up items (Rubin & Rubin, 2012). My initial discussions with 16 participants lasted 30—60 minutes. In-person interviews occurred in a private office. Virtual interviews happened in a locked, password-protected space hosted on the Zoom platform. None of the participants opted for phone interviews. No matter the format, audio from each interview was captured using a digital Olympus recorder. Video recordings of participants were not created. Recordings of interviews were labeled according to participants' numeric identifiers to ensure their privacy.

After starting the recordings, participants were asked about their information needs, everyday life barriers, information practices, and perceptions

of the institution's people, information, norms, and tools (Appendix E). Those questions stem from students' everyday life studies, particularly research on students with autism (Cai & Richdale, 2016; Cox et al., 2017; Pionke et al., 2019). As I talked with participants, I used inclusive, identity-first language (e.g., "on the autism spectrum," "autistic traits," "educational strategies") recommended by Bottema-Beutel et al. (2020). In addition, given that these interviews were semi-structured, I remained open to the possibility of asking follow-up questions of participants (Olson, 2016). As they became necessary, asking follow-up questions helped me achieve a greater, more nuanced understanding of participants' information practices. After each participant's first interview, I delivered a \$25.00 electronic gift card to their institution's bookstore.

Everyday Life Maps

Aside from conducting interviews, information world mapping is another technique used to investigate participants' information practices. As defined by Jaeger and Burnett (2010), an information world is comprised of a population's localized and trusted sources of information (e.g., relatives, friends, peers), which are shaped by the population's broader socio-cultural contexts (e.g., access to technologies, federal regulations, socio-cultural norms). Applying Jaeger and Burnett's scholarship, Greyson et al. (2017) demonstrated that information world mapping is a participatory design method for eliciting rich data from interviewees with poor literacy and those who are uncomfortable with lengthy interviews. Also, this technique is beneficial for discovering sources and behaviors not shared verbally by participants. Upon inspecting 24 studies of interventions for students on the autism spectrum, Anderson et al. (2019) concluded that graphic organizers are effective for helping autistic participants communicate. Given the advantages of using this technique, I asked participants to create information world maps, which I coined *everyday life maps*. Expanding on recommendations offered by Greyson et al. (2020), participants depicted specific components of an everyday life map:

- Information needed to solve everyday problems
- Physical, electronic, and personal sources of information
- Technologies that help participants use information
- People who assist participants with using information
- Technologies that help participants share information
- People with whom participants share information
- Places, either physical or virtual, where participants “do things with information” (p. 156)

Drawbacks to mapping include the amount of time it takes to complete each drawing, participants’ discomfort with their artistic talents, and the potential for oversimplified information world maps (Greyson et al., 2017). Given the amount of time it might take for each student to complete a drawing, I instructed participants to prepare and submit their pictures in the week between their initial and follow-up interviews. To avoid the misplacement of maps, students who were provided with hard copies during in-person interviews also received an electronic version. To help participants become more comfortable with mapping, I reviewed the prompts, demonstrated the submission process and asked them if any accommodations were needed to complete their pictures. Further, I explicitly stated: “Please do not worry about your artistic ability.” In addition, I told them not to include any personal identifiers in their drawings to protect their anonymity. Finally, participants uploaded pictures of their maps from their mobile devices using another Qualtrics form (Appendix F). Thirteen participants completed everyday life maps.

Follow-Up Interviews

Once each student participated in an initial interview and submitted their map, I conducted a follow-up interview a week following the initial session. Thirteen participants completed follow-up interviews. During the second interview, which lasted 30–60 minutes, I asked the participant about their drawing to collect the richest data possible (Appendix E). Asking participants about their drawings helped me clarify their specific elements and my interpretations of them

so I could compare codes across the data. After each follow-up interview, I delivered a \$25.00 electronic gift card to the participant's institutional bookstore.

Transcribing Interviews

Following the interviews, I utilized Verbit's (2022) professional transcription service to generate transcripts of the audio recordings. As a profoundly deaf researcher, hiring Verbit enabled me to ensure that participants' words are most accurate because the provider agrees to correct inaccuracies at no additional expense. In addition, I listened to each recording multiple times to ensure the transcriptions' accuracy while comparing the audio with its transcript. As needed, I asked colleagues to verify unclear portions of participants' recordings and transcripts to bolster their accuracy.

Data Analysis

Initial and Axial Coding

Consistent with GTM, I rigorously analyzed data during multiple initial and axial coding rounds (Denzin & Lincoln, 2018). Rounds of initial coding, or line-by-line analysis, allowed me to extract descriptions from participants' transcripts (Saldana, 2015). Since participants described their maps during follow-up interviews, I similarly coded those descriptions to analyze their everyday life maps. Once I pulled the initial codes, I performed axial coding, which involved clustering codes into abstract categories (Corbin & Strauss, 2015). Chapter Four describes the initial and axial coding cycles in detail.

Theoretical Coding

During the final rounds of theoretical coding, which followed initial and axial coding, I prioritized and clubbed the categories into overarching themes (Charmaz, 2014). Emergent themes uncovered in participants' words and drawings eventually reached saturation, meaning that any new data overlaps with the existing data (Charmaz, 2014). However, until I reached theoretical saturation, I continued collecting and analyzing data. In Chapter Four, I elaborate on my theoretical coding. Then, I propose and apply a theoretical model in Chapter Five.

Ethical Considerations

To ensure the safety and well-being of participants, I made several ethical considerations. First, the rigorous IRB application process bolstered the legitimacy of my research and required me to consider the ethical implications of the decisions I made during the study. Second, I maintained participants' confidentiality throughout the recruitment, data collection, and analysis phases (e.g., redacted identifiable information). Finally, students' participation was strictly voluntary, and they were permitted to withdraw from the study at any time.

Ensuring Rigor

GTM afforded flexibility in collecting and analyzing data to ensure findings were rigorous (Morse et al., 2016). As new data emerged, I constantly compared new codes with existing codes to achieve this goal. Given the subjectivity of GTM, researchers may draw different conclusions from a dataset (Denzin & Lincoln, 2018). To address this concern and bolster the trustworthiness of findings, I assessed intercoder reliability by inviting two researchers to code a sample of transcriptions and everyday life maps (O'Connor & Joffe, 2020). Also, I utilized member-checking by allowing participants to review and provide feedback on my coding (Lindlof & Taylor, 2017). My intercoder reliability and member-checking efforts are described in Chapter Four.

CHAPTER FOUR:

FINDINGS

Chapter Four presents findings from conducting interviews with and collecting everyday life maps from students on the autism spectrum. First, I begin this chapter by describing the participants, including their demographic traits and the accommodations and assistive technologies they use in everyday life. Second, I detail the initial and axial coding cycles. Third, I present findings for RQ(a) and RQ(b). Fourth, I share participants' recommendations for providing structural agency. Fifth, I articulate the significance of participants' everyday life maps. Finally, I describe how I developed themes from the axial codes.

About the Participants

Participants from both institutions included five first-year students, three sophomores, three juniors, four seniors, and one graduate student. Each participant's pseudonym, age, gender, year, academic program, and school is provided in Table 2. The institutions' names are redacted for participants' privacy.

An aggregated summary of participants' university accommodations, and the assistive technologies they use, is provided in Table 3. Participants often receive alternative testing accommodations, such as completing examinations in testing centers. They also receive extended time on tests and assignments. Classroom accommodations include permission to take breaks as needed, notetaking services, preferred seating, and priority registration. In addition, some participants receive adjustments to their institution's attendance policy and depend on service animals to reduce their anxiety. Revealed during participants' interviews, most students do not use assistive technologies because they neither need the tools nor realize they are available. Some participants, however, benefit from using captioning and transcription services, fidget objects, noise-canceling earbuds, headphones, and tablet devices (e.g., Apple iPad, Bamboo tablet). Participants' applications of their accommodations and assistive technologies are explained later.

Table 2. Participants' Demographics

Pseudonym	Age	Gender	Year	Academic Program	School
"Curtis"	18	Male	First-Year	Nuclear Engineering	School A
"Justice"	18	Nonbinary	First-Year	Computer Science	School A
"Madison"	18	Undisclosed	First-Year	Neuroscience	School A
"Malcolm"	18	Male	First-Year	Aerospace Engineering	School A
"Raymond"	18	Male	First-Year	Business	School A
"Bailey"	20	Male	Sophomore	Political Science	School A
"Rachel"	19	Female	Sophomore	Environmental & Soil Science	School A
"Rory"	19	Nonbinary	Sophomore	Pre-Medicine	School A
"Julian"	20	Nonbinary	Junior	History & Philosophy	School A
"Mason"	20	Male	Junior	Marketing	School A
"Opal"	21	Female	Junior	Equine Science & Management	School B
"Gabrielle"	22	Female	Senior	History	School A
"Ruby"	26	Female	Senior	Animal Science	School A
"Sarah"	21	Female	Senior	Mechanical Engineering	School A
"Sasha"	21	Nonbinary	Senior	Civil & Environmental Engineering	School A
"Jayme"	23	Undisclosed	Graduate	Information Sciences	School A

Initial and Axial Coding

Consistent with GTM, I concurrently collected and analyzed data (Morse et al., 2016). Data collection and analysis lasted five months. I began collecting and analyzing data during the first round of initial interviews with seven participants (Table 4). Following these interviews, I performed the first rounds of initial and axial coding of transcripts. Based on participants' responses to my questions, along with their recommended changes, I revised some questions and submitted my amended instrument for IRB approval (Appendix E). The revisions I made included the following:

- Instead of vaguely referring to participants' "primary responsibilities" as students, I divided the questions into two sections: "academic experiences" and "everyday experiences." In the first section, I asked students to discuss a challenging course they took in the past year. In the second half, I asked them to share an everyday decision in the past year. For each section, participants were asked similar questions about (a) challenges they faced; (b) guidelines, rules, and expectations that shaped their information practices; (c) documents or materials used to address their concerns; (d) technologies used; (e) places where information was sought, used, and shared; (f) people involved in their activities; and (g) accommodations or resources they found helpful. Asking participants to recall impactful events, and asking consistent questions between the two sections, allowed participants to provide richer data.
- I grouped questions about participants' "overall experience." Specifically, I asked about the most important questions or concerns they have as students, their means of finding needed information (e.g., information, people), and how their institution enables or constrains their information practices. Grouping these questions, and making the previously mentioned changes, allowed participants to understand my questions more fully and provide richer data.

Table 3. Participants' Accommodations and Assistive Technologies

Accommodations	Assistive Technologies
• Alternative testing location ($n = 11$) • Extended time on examinations and assignments ($n = 11$) • Take breaks from class as needed ($n = 6$) • Adjusted attendance policy ($n = 3$) • Note-taking services ($n = 3$) • Pause examinations as symptoms arise ($n = 3$) • Preferred seating ($n = 3$) • Priority registration ($n = 2$) • Service animal ($n = 2$) • Wear headphones during classes ($n = 2$) • Deliver presentations privately ($n = 1$) • Eat in classes ($n = 1$) • Housing accommodations (e.g., private bedroom) ($n = 1$) • Record lectures ($n = 1$) • Use computer in the classroom ($n = 1$) • None ($n = 1$)	• Noise-cancelling earbuds or headphones ($n = 4$) • Tablet devices (e.g., Apple iPad, Bamboo tablet) ($n = 4$) • Fidget objects ($n = 3$) • Apple Pencil ($n = 2$) • Captioning and transcription services ($n = 2$) • None ($n = 11$)

Once I received IRB approval to use my revised instrument, I performed initial interviews with four students and follow-up interviews with eight participants. During the second rounds of initial and axial coding, I collected and analyzed eight participants' everyday life maps.

To collect more data and bolster the findings' significance, I amended my IRB application a second time to recruit participants from School B. After conducting initial and follow-up interviews with, and collecting four everyday life maps from, four students in School A – and interviewing and receiving a map from School B's participant – I performed third rounds of initial and axial coding.

Consistent with GTM, I achieved theoretical saturation after conducting 21 interviews with 12 participants since the axial codes reflected the data's depth and breadth, and my remaining interviews with four students did not yield new initial codes (Corbin & Strauss, 2015). Hence, my dataset of 29 transcripts and 13 maps from 16 participants was sufficient. It is worth noting that three participants did not complete everyday life maps or follow-up interviews due to health circumstances. Figure 2 depicts the codes present across three rounds of participants' transcripts and everyday life maps.

Trustworthiness of Findings

To verify the findings' trustworthiness, I measured intercoder reliability (O'Connor & Joffe, 2020). Accordingly, I invited two colleagues to analyze randomly selected transcriptions and everyday life maps from each round. During scheduled meetings, we reviewed my codebook (Appendix G) then analyzed the materials. To protect the students' data, coding did not occur outside my presence. Overall, there was above 85 percent agreement among all coders. To determine this percentage, I calculated the number of times my colleagues assigned the same codes I did, then I divided that number by the total number of items coded.

Another way I validated the findings was by engaging in dialogic member-checking (Harvey, 2015). Following each round of data collection and analysis, I emailed my codebook to every participant for them to review and provide

feedback (Denzin & Lincoln, 2018). Of the three participants who responded, there was total agreement. Based on their feedback, I report the findings below.

Structural Agency Concerns

This section addresses RQ(a): *What are autistic students' agentic concerns?* My initial and axial coding cycles revealed participants' concerns regarding the structural agency provided by their institution (Table 5). Participants' concerns include (a) ableism, (b) overstimulation, and (c) psychosocial barriers. Illustrations of each concern are provided in this section.

Ableism

Participants' structural agency concerns include ableism, which Dolmage (2017) defined as follows: "[Academia] powerfully mandates able-bodiedness and able-mindedness, as well as other forms of social and communicative hyper-ability, and this demand can best be defined as ableism" (p. 7). During an interview, Jayme, a graduate student in Information Sciences, shared with me their understanding of ableism: "To me, it's a lot of inherent biases against disabled people in general. It can be on purpose or accidental. And it can have to do with not wanting to accommodate someone with something they struggle with, even if it's something easy." Inaccessible instruction, mischaracterizing autism, and [being] unreceptive to accommodations, are institutional norms which discriminate against this population, intentionally or not.

Inaccessible Instruction. Participants talked about how their professors often provide vague instructions for completing assignments, do not clarify deadlines, and seldom communicate with their students, instructional practices which participants deem inaccessible. Rory, a sophomore Pre-Medicine major, shared their concern about vague assignments:

Table 4. Interviews Conducted and Everyday Life Maps Collected Across Rounds

Coding Round	Initial Interviews	Follow-Up Interviews	Everyday Life Maps
1	7	0	0
2	4	8	8
3	5	5	5
Total	16	13	13

Axial Code	Initial Code	Rachel Bailey	Justice Julian	Rory (1)	Madisc Masor	Curtis	Sarah	Gabrie Raym	Malcol Jayme	Sasha	Ruby (	Opal (	Number	Freq.
Ableism	Inaccessible Instruction	Y	N	Y	Y	Y	Y	Y	N	Y	N	Y	12	75%
Ableism	Mischaracterizing Autism	Y	N	Y	Y	Y	N	N	N	N	Y	N	9	56%
Ableism	Unreceptive to Accommodations	Y	N	Y	Y	Y	N	N	Y	N	N	N	6	38%
Overstimulation	Physical Sensitivity	N	Y	N	Y	N	Y	Y	Y	Y	N	Y	10	63%
Overstimulation	Crowding	Y	Y	N	Y	N	Y	N	N	N	Y	N	7	44%
Psychosocial Barriers	Anxiety	N	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	14	88%
Psychosocial Barriers	Limited Social Awareness	N	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	13	81%
Psychosocial Barriers	Emotional Blindness	N	Y	N	Y	N	N	N	Y	Y	N	N	7	44%
Learning	Using Study Aids	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	15	94%
Learning	Working with Peers Versus Working	Y	N	Y	N	Y	Y	N	N	Y	Y	Y	11	69%
Learning	Consulting Professors	N	N	N	Y	N	Y	N	N	Y	N	Y	8	50%
Learning	Receiving Tutoring	N	N	N	N	Y	Y	N	N	Y	N	Y	7	44%
Building Life Skills	"Panic Researching" for Living Indepe	N	N	N	Y	N	N	N	N	Y	Y	N	6	38%
Building Life Skills	Researching Careers	N	N	Y	N	Y	N	N	N	Y	Y	N	5	31%
Building Life Skills	Becoming Financially Literate	Y	N	N	N	N	N	N	N	N	N	N	1	6%
Managing Perceptions	Managing Others' Perceptions	N	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	14	88%
Managing Perceptions	Managing Self-Perceptions	N	Y	N	Y	Y	N	Y	Y	Y	Y	N	12	75%
Practicing Self-Care	Achieving Balance	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	15	94%
Practicing Self-Care	Accepting Support	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	15	94%
Practicing Self-Care	Finding Solace	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	15	94%
Design Accessible Instruction	Provide Explicit Instructions and "Spo	N	N	Y	Y	N	Y	Y	N	N	N	Y	6	38%
Design Accessible Instruction	Make Information Accessible	N	Y	Y	N	Y	Y	N	N	N	N	N	5	31%
Design Accessible Instruction	Promote Hands-On Learning	Y	Y	N	N	Y	N	N	N	N	N	Y	4	25%
Reduce Mischaracterizations	Form Community Partnerships	N	Y	N	N	N	N	Y	N	N	Y	N	4	25%
Reduce Mischaracterizations	Inspire Autism Allies	N	N	N	N	N	Y	N	N	N	Y	N	4	25%
Reduce Mischaracterizations	Promote Accessible Events	N	Y	N	N	N	N	N	N	N	N	N	2	13%
Enhance Functioning	Improve Disability Support Services	N	N	N	Y	N	Y	N	N	N	N	N	4	25%
Enhance Functioning	Create Sensory Spaces	N	N	N	N	Y	N	Y	N	N	N	N	2	13%
Enhance Functioning	Provide Life Skills Training	Y	N	Y	N	N	N	N	N	N	N	N	2	13%

Figure 2. Codes Present Across Participants' Transcripts and Everyday Life Maps

I have assignments from some classes that are vague, and I personally need solid instructions that tell me what I need to do, how I need to do it, and what it's going to look like when it's done. And I tend to struggle with those assignments a lot because I don't have an outline. I don't know what to do. I don't know where to go. So, I end up just overthinking it a lot, and that really trips me up because I end up doing something completely different than what the professor wanted or what was intended.

Sarah, a senior Mechanical Engineering major, described her struggle with a recent assignment: "Just this semester, one of my assignments said, 'Include a graph.' So, I did have a graph, but I did not include a title or a legend or axis because the assignment didn't tell me to, even though I was expected to because that is implied." Even during examinations, students may be uncertain of their professors' expectations, as Raymond, a first-year Business student, articulated: "Our exams are pretty much just short answers, make a small paragraph about this one question, and it can be difficult at times, because we don't really have any direction, and we don't really know what the teacher wants."

Participants are also challenged when deadlines are unclear. Rachel, a sophomore Environmental & Soil Science major, stated: "A common problem for me is going into a class thinking I'm prepared for the day and then finding out I'm missing something. It's not that I didn't do the assignment, but I just misunderstood what we were supposed to be doing for that period in between." Inconsistency when giving assignments exacerbates this concern, as Malcolm, a first-year Aerospace Engineering student, shared during an interview: "One of my professors is typically inconsistent about uploading homework to Canvas. He always gives the same amount of time to complete the assignment when he does upload it, but he's very inconsistent in his timetable for grading it and putting it on Canvas, or whether he acknowledges that you've even turned it in. Many times, it can be frustrating."

Professors' limited communication is further concerning for students like Opal, a junior Equine Science & Management major, who cannot comprehend information simply from watching recorded lectures or reading textbooks:

We have these [recorded] lectures that we watch. They're our online lectures, so they ask us a question and we must try to answer it, but sometimes the way they've explained it made no sense, so of course we get the question wrong, and then we lose points. We can't ask a question if we learn it the wrong way because it's not live . . . There was one [lecture] where it paused for us to answer the question and I got it wrong. Then after I answered it, the text below the question said, 'I'm guessing you didn't read the textbook,' with a frowny face. I spent a half an hour reading the textbook and still didn't get it. In another one, I got the question wrong, and she said, 'I'm guessing you probably got this wrong because they didn't teach this yet, so here. Let's show you what you need to know to do this.' Then in class, she's always saying, 'You've got to study. You've got to read the textbook. You've got to work on the practice problems.' She goes over that in every class. I'm like, 'We're trying, and it's not working.'

Mischaracterizing Autism. Participants talked not only about inaccessible practices, but also people's erroneous attitudes toward autism. Rory described how autism is mischaracterized: "Not enough people talk about [autism] and it's still considered, I don't want to say taboo, but many people still don't understand it. It's frustrating because I have seen how other people treat neurodivergent kids." In fact, Opal was insulted by depictions of autism in a recently released movie starring a popular musician:

People don't even bother to realize that there's a spectrum and not everybody is violent or screaming or thrashing or makes

these weird facial expressions. That's not what autism is. It's a spectrum. So that kind of media portrayal is harmful to autistic people. One autistic person I've ever known has been like this. Out of the hundreds of autistic people I know, one has been like that. One.

Jayne described how mischaracterizations affect them interpersonally: "If people find out I'm autistic, their first instinct is, 'I never would have been able to tell.' Or 'Girls can have autism, too? Oh my gosh. Really?' And I'm done with it. I'm like, 'Yeah, you're not a doctor who knows the criteria or someone who specializes in autism. Or maybe it's because I don't tell you all my symptoms.'"

Participants revealed that disability support services in their institutions sometimes mischaracterize autism. In fact, Julian, a junior History & Philosophy student, described negative encounters with their coordinator: "Sometimes, I'll go to my professors before going to my [disability support services coordinator]. I'll be like, 'Hey, I can't get an extension through [disability support services] because I was told I didn't need [the accommodation], and that my need for it wasn't real. Can I have an extension, please?'"

Even participants' families struggle to understand autism, as Sasha, a senior Civil & Environmental Engineering major, disclosed:

I've been around [my family] my entire life, but it has been interesting now that I've gotten my diagnosis. I don't think my parents believe that it's correct. They have a lot of internalized stigmas about autism, so they think it's this horrible thing. So, as I've been going through this process, they have not been enthusiastic about it. That's different from the experience I've had with my roommates. [My friends] were like, 'Yeah, that tracks.' . . . It's different because, I think, [my parents are] from a different generation. Autism was more stigmatized in their generation. So, I think there's internalized stigma that they must overcome before they can accept [my diagnosis].

Unreceptive to Accommodations. Participants also believe that professors are unreceptive to their accommodations. For example, Justice, a first-year Computer Science major, depicted their non-major professor as a monster who exclaims, “No accommodations!” (Figure 3). Further, although professors must adjust their attendance policies for Gabrielle, a senior History major, she encountered resistance:

The professor was like, ‘Is this going to be a problem?’ I was like, ‘Well, I don’t know. You tell me.’ I didn’t know how to respond. But he, overall, was very hostile towards it. He was like, ‘Well, you have to be in class,’ and I was like, ‘Yeah, I’m just giving you a heads up. I can’t put a number on it, but maybe a once-a-week thing, and I’m not going to be gone the whole class period. I just need to reset my brain.’ He was not receptive to that. I did not feel super comfortable leaving his class, given that the first response was, ‘Is this going to be a problem?’ Like, what the heck, dude?

Students may even receive accommodations for wearing noise-cancelling headphones to ease information-processing. However, Julian described the pushback they receive from some professors: “I’ve had a couple of professors think that [my earbuds] are Bluetooth headphones. And I’m like, ‘You can look at them. You can touch them.’ They’re just little loop headphones that I can stick in my ears to dampen the sound around me. Or [professors will] say that I won’t hear them properly. And I’m like, ‘I don’t know how to tell you, but I’m going to do this anyways.’”

Participants shared professors are sometimes unreceptive to accommodations which modify assignments, particularly adjustments that allow for additional time on assignments. Rory shared: “I’ve had a comment from my public speaking professor. She was like, ‘If you have trouble with the time constraints, then maybe you just need to take a different public speaking class because the time constraints can’t accommodate you.’”

Overstimulation

Overstimulation is a second agentic concern participants expressed. Physical sensitivity and crowding are features of overstimulation which impede information-processing.

Physical Sensitivity. Sensitivity to sounds, textures, and odors comprise physical sensitivity. Sarah offered an example of how sounds can be overstimulating: “One of the lessons [in a psychology class] was on sound, noise, and how the brain interprets that. I had issues doing that lesson because, to demonstrate, the teacher had loud noises that I was not okay with. Since getting my diagnosis, I can now leave the classroom if that happens again, which I’m relieved to hear.”

Textures are also overstimulating for participants, as Julian described: “Up until recently, I only used my iPad for notetaking. I had an Apple Pencil, and that’s what I would use. I found that easier than paper because this will sound odd, but the texture of paper messes with me a lot. So, I prefer writing on glass.”

Sensitivity to odors is further of concern to some participants. Sasha described the overstimulation they encountered when taking a marine biology course: “The smell of the chemicals used in the preservatives overwhelms me. So, I would wear multiple masks to mask the smell. I like fish, but it was a difficult class to take.”

Crowding. Participants shared that crowding is another form of overstimulation which hinders information-processing. Bailey, a sophomore Political Science major, avoids studying in crowded places: “When I’m studying, I can’t go to the library or anywhere that’s super public to work, because trying to focus on my work while there’s other things going on, people walking past me, things like that, makes it extremely difficult.” Gabrielle, like numerous participants, cannot effectively study in academic libraries: “Even if I’m in the study carrels on the sixth floor and nobody’s up there, there’s a lot of people in that building, and anybody could walk by and look at me. Autism is weird. That shouldn’t throw you off for somebody to walk by and look at you, but it does.”

Psychosocial Barriers

Beyond ableism and overstimulation, participants discussed several psychosocial barriers which impact everyday life: (a) anxiety, (b) limited social awareness, and (c) emotional blindness.

Anxiety. Adjusting to the increased workload of higher education generates anxiety. As Justice illustrated in their everyday life map (Figure 3) and explained in an interview:

The workload is killing me. My family isn't explicitly putting any pressure on me, but I know that I do have a lot riding on my success in college. If I don't do well in college, my parents will have to support me for longer. Plus, I was the smart kid of the family, and everyone is expecting me to go to college and do well. I really like college, but I'm having to cope with the fact that I am now average in college.

Like their peers, Madison becomes anxious when their workload increases, sometimes to their detriment:

I'm pushing myself, like, 'You've got to do this even if you don't feel well, even if you're stressed out, because then you're going to get even more stressed out.' And that's something I struggled with in high school, too. I would get so stressed out and anxious that I would not go to school, and then it would build up until things were just crazy and I was stressed out to the max. I haven't done that this semester to the extent I did in high school, but I did for a few weeks.

Overdue assignments exacerbate Curtis' anxiety: "Sometimes, I'm like, 'Alright, let's see if I can try to do this, even though it's a few weeks overdue. Let's see if I can get it accomplished.' But most of the time, it is a lost cause."

My Drawing Participant ID 1103

In this space, please draw an illustration of how you have balanced the academic and everyday demands of being a student over the past year. Consider including any of the following items:

- Challenging assignments
- Major everyday decisions
- Information or resources needed
- Documents or materials used
- Technologies used
- University accommodations used
- People involved
- Places visited

Do not worry about your artistic ability. Your drawing will be anonymous.

Following the steps below, please upload a photo of this entire paper before your final interview:

1. Visit the online submission form by using your phone's camera to scan the QR code on the right
2. Enter your Participant ID, which is at the top and bottom right of this paper
3. Upload your photo using the online form

Participant ID 1103

Figure 3. Justice's Everyday Life Map

Codes and Descriptions of Symbols in Everyday Life Map

1. Anxiety – Workload (e.g., assignments, syllabi) exacerbates participant's anxiety
2. Unreceptive to Accommodations – Participant's professor, who is depicted as a monster, refuses to implement needed accommodations
3. Mischaracterizing Autism – Disability support services' alternative testing policies do not help participant satisfy information needs
4. Anxiety – Collapsing under a heavy workload leaves the participant feeling overwhelmed
5. Accepting Support – Participants' mother stays in contact by phone

Scheduling disruptions even yield panic attacks. Bailey shared with me:

I had an exam, so I scheduled it with [disability support services]. Then, I had a panic attack, and I missed it. So, I tried to reschedule it, and they said, 'Oh, we can't do that.' They asked me to come in and take the exam. They emailed me at 10:00 in the morning and asked me to come in at 2:00 to take the exam. I did not appreciate that . . . For people with anxiety, at least for myself, there can be a lot of anxiety around tests. So, I need two days or so to mentally prepare myself. Not just to academically prepare, but to be ready for that environment.

Although Ruby, a senior Animal Science student, could seek guidance from her professors for managing the workload, she fears approaching them: "I'm always afraid that they'll think I'm trying to get off easy, or I'm asking too much, or I didn't try hard enough . . . It's an internal fear. I've acknowledged that it's not logical and that I should still ask, but it's still in the back of my mind."

Participants discussed that anxiety stems not only from academics, but also from their everyday concerns. For example, Malcolm became anxious when securing housing with his friends:

It was taking us a very long time to find somewhere off campus, and I did get extremely worried that I wouldn't have anywhere to stay. Because I was waitlisted for on-campus housing, at one point I was extremely worried that I wouldn't be able to find anywhere to stay. I'd have to commute from home, and that would've been an absolute nightmare.

Additionally, participants talked about their special interests, particularly how they can be distracting and anxiety-inducing. Referencing her everyday life map (Figure 4), Sarah is distracted by her special interest in a controversial shock therapy device:

There has been some back-and-forth legal stuff with the [Food and Drug Administration] about whether to ban the graduated electronic decelerator. It's basically a shock device. I want to hear about [this news]. I want to know more. Specifically, because this device is used by a center to help control the behaviors of people with mental illnesses, especially people with autism, that makes me very upset. Just reading about all that makes it hard to do schoolwork.

Limited Social Awareness. Participants possess limited social awareness, or behaving appropriately in conversations, forming friendships, and recovering from social missteps. Knowing how to behave appropriately in conversations is a concern Opal expressed:

I don't always know if I'm doing something the right way or if I'm talking to someone that is nonverbally telling me that they don't want to talk. That makes me hesitant to approach people I don't know because I don't know what I'm supposed to do. I don't know how I'm supposed to react, so I tend to avoid strangers unless they come up to me first, but I'm trying to get better.

Forming friendships is also difficult for participants like Sasha:

Figuring out how to make friends is harder. I feel like that's a problem everybody has, but I think it's harder for autistic people. I happened to get put in a project group the first semester of freshman year. And I live with that person now, so that worked out well. It took a long time for me to be comfortable around them, though, because [it was a] new place, new person, new friendship, relationship. It was fine the more time I spent with that person and our other friends.

Recovering from social missteps can be problematic for participants. Gabrielle said: "If I say something I didn't mean to say in a discussion, then I'm

going to be thinking about that the rest of the discussion and not what I'm supposed to be thinking about, whereas I think a non-autistic student would not have as much trouble." Like other participants, Raymond blames himself for those missteps: "If there's ever an awkward misunderstanding, I always blame it on myself. I can't blame the other person, so I can only blame myself. I don't know all the social rules, so if something happens, I default to it being my problem." These missteps even occur when communicating with professors, as Rory shared:

Sometimes with talking face-to-face to a professor, there are times when I feel uncomfortable. Just finding the words, sometimes I don't know how to explain my frustrations. And so, I will not be productive in telling my professor what I'm struggling with. It would be something like, 'I'm struggling to understand this concept,' but instead, I would say something completely different than I would intend. Sometimes it's rude or blunt. It's happened multiple times a semester. I will just straight up be like, 'This assignment is stupid.' It's not because it is stupid. It's because I'm frustrated, and I don't know how to communicate that frustration.

Emotional Blindness. Finally, participants are emotionally blind when interpreting satirical writings or symbolism. Julian shared: "I had an assignment, and I completely missed the satire element to it. But it was difficult because I looked up the assignment online and asked other people, and nobody mentioned the satire element to me. So, I completely missed it because it's just not something that comes to mind." Symbolism is also of concern, Bailey illustrated: "[An assignment] was difficult for me because it involved a lot of symbolism, and sometimes that can be very difficult, just understanding that what's written on paper has a deeper meaning." Sharing those concerns, Curtis stated: "I run on logic, so I'm quite blind to emotion."

Resulting Information Practices

This section addresses RQ(b): *What are autistic students' resulting information practices?* Presented in Table 6, participants' information practices include (a) learning, (b) building life skills, (c) managing perceptions, and (d) practicing self-care. Examples of participants' information practices are shared.

Learning

Participants' information practices for learning include (a) using study aids, (b) working with peers versus working independently, (c) consulting professors, and (d) receiving tutoring.

Using Study Aids. To learn, participants use study aids, including tablet devices, supplementary videos, mobile applications, and sensory tools (e.g., noise-cancelling headphones, fidget objects). Study aids were discussed by 94 percent of participants. Using tablet devices, for example, helps students such as Opal record notes during lectures: "I like to use the split screen feature because I can have lecture slides pulled up online and I can have OneNote on the other side. I can write my notes with the Apple Pencil, or I can go back later and say, 'Alright, I need to work on this more because I don't quite get it.'" If materials covered during lectures do not make sense, most participants rely on supplementary videos, as Sarah described: "Especially for math classes, if I have difficulty learning from the instructor, then I will seek out supplementary videos to try to understand the concept better before I go to complete the assignments."

When studying, participants may use mobile applications to aid information-processing. For example, Madison enjoys using Cram:

If you go on cram.com, C-R-A-M. And I type it out, make the flashcards. And then I go on the app, and it gives me the flashcards, but it also gives you 'cram mode,' which is cool because if you get it right, you press the checkmark. And whenever you get it wrong, it stays there. So, then every time you get them right, you go on to the next round, and the ones

you don't get right stay in that round, and you do that round until you get to the next round. So, it's cool, and it helps a lot.

Aside from tablet devices, supplementary videos, and mobile applications, participants use sensory tools, which can reduce overstimulation. Bailey talked about one tool, noise-cancelling headphones, which reduces sensory barriers:

I have earbuds and backup headphones; they're noise canceling. So, if I go somewhere that's a little noisy to get work done, I can put those in, and it helps me tune out some of the sensory information, mainly the audio stuff. And I can have nothing on and no noise, I can play white noise – like the ocean crashing, rain – or I can play music, and it helps me. So, that's only five senses and eliminates one of them.

Other sensory tools include fidget objects, which enhance participants' focus. Ruby shared:

It's difficult for me to focus. There are days where I feel irritable, and it's difficult for me to stay still to learn anything . . . I keep fidgets on me. I have a fidget cube. I have a few other things. I have a worry stone. It has a thumb indentation and feels nice to rub. Doing that while I'm listening helps.

Working With Peers Versus Working Independently. Participants shared that while working with their peers may be uncomfortable, their learning is enhanced. Ruby described the value of teamwork and information-sharing, which she also depicted in her everyday life map (Figure 5):

[Studying with peers is] helpful because we're able to pass information back and forth, like, 'Hey, what did he say in class today? I didn't understand.' And this person can clarify. Or 'I don't understand this part of the assignment. Can someone explain it to me?' And they can send a quick message to let me know. We'll even share Quizlets through GroupMe.

Codes and Descriptions of Symbols in Everyday Life Map

1. Physical Sensitivity – Distracting sounds cause anxiety and disrupt information-processing
2. Achieving Balance – Participant maintains a detailed daily schedule to reduce anxiety
3. Anxiety – No amount of time the participant spends sleeping or studying reduces stress
4. Achieving Balance – Taking notes enables the participant to manage her assignments
5. Anxiety – Participant feels anxious about people not adhering to masking mandates during the 2019 Coronavirus pandemic
6. Anxiety – Participant experiences rapid heartbeat due to her anxiety
7. Anxiety – Drawings of cortisol and serotonin chemicals represent participant's anxiety
8. Anxiety – Information overload, which is illustrated by multiple browser tabs, yields anxiety
9. Anxiety – Participant's efforts when completing assignments may prove futile
10. Inaccessible Instruction – Professor's unclear directions for assignments lead to poor submissions
11. Finding Solace – Doodling triangles allows the participant to process information
12. Inaccessible Instruction – Completing handwritten assignments for programming course increases uncertainty
13. Anxiety – Participant is afraid of the public safety consequences of her decisions as a future engineer
14. Finding Solace – Listening to calming music helps lower anxiety
15. Anxiety – Participant's special interest in a controversial shock therapy device exacerbates anxiety and impedes focus

16. “Panic Researching” for Living Independently – Participant has a pressing need to continue researching psychological disorders which can explain their behaviors

Table 5. Participants' Agentic Concerns

Concerns (Axial Codes)	Features (Initial Codes)	Participants (Frequency)
Ableism	Inaccessible Instruction	<i>n</i> = 12 (75%)
	Mischaracterizing Autism	<i>n</i> = 9 (56%)
	Unreceptive to Accommodations	<i>n</i> = 6 (38%)
Overstimulation	Physical Sensitivity	<i>n</i> = 10 (63%)
	Crowding	<i>n</i> = 7 (44%)
Psychosocial Barriers	Anxiety	<i>n</i> = 14 (88%)
	Limited Social Awareness	<i>n</i> = 13 (81%)
	Emotional Blindness	<i>n</i> = 7 (44%)

Working with peers is not solely about mastering knowledge. Collaborating bolsters accountability, Opal stated: “My study group helps me. If other people around me are working and studying, I feel more motivated to stay on track and not procrastinate, so if I can be around other people when I’m doing an assignment, they help me stay on track.” Outside of study groups, roommates hold each other accountable and help prevent distractions. Julian derives value from studying with their roommate:

We have two different couches. I’ll sit on one, she’ll sit on the other, and we will put our phones on the table face-down, so we don’t get notifications. And we will not touch our phones until we have finished with what we are doing. If we try to leave the room, we will shame each other nicely for trying to leave before we have finished the assignment. Just like, ‘Hey, stay in your seat. We both must be here and do this right now until we finish our work.’

Since social interactions heighten participants’ anxiety, some participants prefer working on assignments alone. Rachel shared: “I have one or two peers or friends that I work with a lot. But I don’t interact with very many people, typically. So, I enjoy working on things alone.”

Consulting Professors. Participants seek clarification from their professors if reading materials or consuming lectures are confusing. Opal shared with me:

[Some professors] take time outside of their office hours to explain things. I can email them and ask questions, and they’ll try to explain it in ways I can understand . . . [We] could go to [one professor’s] office hours two or three times a week, for several hours a day online, so that helped. If we asked a question, she would turn on her whiteboard screen. Then she would work the problem out, so we understood it.

Because socializing is problematic, some participants prefer having scripted conversations with professors. Sarah illustrated this idea: “Most of my interactions with professors have been very structured and I know what to expect from them, such as I go to office hours to ask a question. So, I usually find it easier to talk with my professors as opposed to talking to my peers.”

Receiving Tutoring. Finally, participants learn by receiving tutoring. Sasha received help from Teaching Assistants in her marine biology course: “The [Teaching Assistants] are helpful. If we had a question about any of the fish, they would always have an answer or they would find the answer and come back to tell us. They had some study tricks and uploaded lecture videos as extra materials.” Similarly, Madison receives mathematics tutoring: “I like going to [redacted] . . . We have a Discord, so if you have any questions, you can say, ‘Hey, what is coming to you?’ They’ll be like, ‘Okay, here you go. That’s what that means.’ They know so many things, so that’s cool. You can also ask them, ‘Can we do a study session?’”

Building Life Skills

Participants build life skills by (a) “panic researching” for living independently, (b) researching careers, and (c) becoming financially literate.

“Panic Researching” for Living Independently. Living independently can heighten participants’ anxiety, and in select cases, cause panic attacks. When finding a place to live, Julian engaged in “panic researching”:

I have an anxiety disorder. I feel that more information is better. So, when I get panicked about something, I will learn all the information I can about it. Or if something in the news worries me, I need to learn everything I can. I call it ‘panic researching’ because I am panicking. But I’m also getting so much information and learning from it, so it’s useful.

My Drawing

Participant ID _____

In this space, please draw an illustration of how you have balanced the academic and everyday demands of being a student over the past year. Consider including any of the following items:

- Challenging assignments
- Major everyday decisions
- Information or resources needed
- Documents or materials used
- Technologies used
- University accommodations used
- Objects used
- People involved
- Places visited
- Problems faced

Do not worry about your artistic ability. Your drawing will be anonymous.

1

studying



Library

2

Balancing Meals



3

E-mail



asking for help

4



Medical help

5

Going to class



6

#1 Team



collaboration

7



getting sufficient rest

Following the steps below, please upload a photo of this entire paper before your final interview:

1. Visit the online submission form by using your phone's camera to scan the QR code on the right
2. Enter your Participant ID, which is at the top and bottom right of this paper
3. Upload your photo using the online form



Participant ID _____

Figure 5. Ruby's Everyday Life Map

Codes and Descriptions of Symbols in Everyday Life Map

1. Finding Solace – Participant studies in quiet, isolated places to avoid overstimulation
2. Achieving Balance – Remembering to eat healthily is essential to achieving balance
3. Accepting Support – Asking professors, peers, and relatives for help is important to achieve balance
4. Achieving Balance – Receiving adequate healthcare is fundamental to achieving balance
5. Achieving Balance – Participant manages her schedule to maintain classroom attendance
6. Working with Peers Versus Working Independently – Participant believes that working with peers requires teamwork and bolsters accountability when learning
7. Achieving Balance – Remembering to get plenty of sleep helps the participant achieve balance

Researching housing proved challenging and anxiety-inducing for Malcolm and his roommates:

There were times when I felt like I didn't have enough information because although the university does provide a list of places off campus that are good for students, it wasn't a comprehensive list . . . It was a list of the places with no other information. Maybe for a few of them it had the website.

Researching Careers. Participants browse websites to research careers and identify internships. Justice shared their desire to learn more about the cybersecurity industry:

The websites I go to mostly end in .org because they're by cybersecurity organizations, computer organizations looking to hire new people and give you some information about the job. But I also like reading about people who have the job, so I can get the good, the bad, and the ugly because the organizations are looking to hire people and frame it in the best light possible. So, I guess that means excluding the not-so-glamorous parts.

Jayme, an aspiring academic librarian, identified possible internships:

I was looking things up because I knew [this university] existed and I was like, 'Do they have internships? What can I do?' And so, I emailed who's my supervisor now and I was like, 'I'm a grad student. I'm looking to hopefully do my practicum. I was wondering if there's any opportunities.' Thankfully, I emailed her before anyone else did. I had to do a lot on my own and I was worried about it, but it's turned out good.

Becoming Financially Literate. One participant, Rachel, discussed the importance of becoming financially literate:

For a long time, I was winging it. Recently I've been making my budget page in Notion, so every month, I have a way to track everything I spent and where it went. And it makes me accountable because it shows me if I'm negative or positive for that month. And it makes me feel not guilty . . . One of my biggest issues is hyper-focusing on my special interests a lot. And they tend to be like video games or comic books, which are very easy to spend money on.

Managing Perceptions

Participants engage in perception management, including managing others' perceptions and their self-perceptions being on the autism spectrum.

Managing Others' Perceptions. To manage others' perceptions of themselves, participants either conceal or disclose their autism. Participants may prefer their peers not know about their diagnoses. For instance, Mason, a junior Marketing major, takes pride in concealing his autism diagnosis: "Not one of [my peers] knows I have autism, which is the coolest part. None of them would ever guess I have autism. Most of them don't even know I get accommodations. The ones that do, they assume it's for [attention deficit hyperactivity disorder]." Bailey fears being outcast by sharing his diagnosis:

The fear of being an outcast that's a huge fear that drives me. I've never told any of my close friends that I have autism, but I told them that I'm socially inept, so, 'Help me out.' In fact, I've had friends pick out outfits I should wear. Instead of doing it myself, my whole closet has stuff that people told me, 'Oh, here's a cool thing for you to wear.' So, I give them a little bit of information, not all of it.

Masking is understood by participants as their ability to replicate social cues for appearing normal. Gabrielle shared during an interview:

I spent most of my life trying hard to be normal and picking up on everything I could, being a complete sponge of social norms and cues, how to act and talk. So, that is what I spent most of my time doing, trying to fit in and speak the way everyone else is speaking and do the things everyone else is doing, and not let it be known that there are things that bother me.

Similarly, Madison revealed: “I’m always thinking about what kind of eye contact do I make? I need to make sure I’m having the right tone of voice, not doing any weird movements, and saying things that are appropriate.”

Participants like Raymond conceal their autism by applying information they gather online: “I learned how to socialize better by going online and seeing how. And I was able to develop one close relationship with somebody, which helped me even more.” Justice also learns social cues by reading psychology textbooks: “I rehearse conversations in the mirror a lot and read about people. Sometimes, I look at a psychology book or a website to learn how neurotypical people function, but I usually copy them.” Once they learned to mask their autism, Sasha crafted a unique persona for each of their peers:

Coming into college and having to make all new friends was a stressful experience, and it was stressful because of the autism . . . I would curate a different personality for each person I knew, which was a lot of effort. So, when I would meet someone, I would be nervous and quiet the first few times I interacted with that person before I figured out what aspects of my personality, I should put at the front so that I will be friends with them. And that takes so much mental energy and causes so much anxiety.

Participants not only conceal their autism from people in their everyday lives (e.g., peers, professors, relatives), they even mask their diagnoses when seeking employment, which Rory shared:

Whenever I was doing [a recent job interview], it was hard for me to [share my diagnosis] . . . Part of me is afraid to because a lot of people have a stigma against autism, in which, ‘Oh, if this person is high functioning, they won’t be competent in the job. So, that’s an underlying fear that I have. It’s not what they said to me; it’s just something that I’m afraid of.

Whereas some participants mask their autism, others disclose their diagnoses. For example, sharing information helps Gabrielle’s friends understand her autism: “Sometimes, [disclosing] can be helpful, and sometimes it can throw people off. You must, in my experience, gauge if you’re good enough friends with somebody, and it’s how you tell them, but that can help people understand why you get anxious about certain things, and why you’re asking, ‘Hey, was it weird when I did this?’” Disclosing their autism also helps Rory’s relatives understand them better: “There are times when I will stim, and I’m open with that if [my family members] want to learn about it or understand what’s going on. I’m one of the only autistic people in my family, so throughout my life, it’s been like, ‘Why do you do that kind of stuff? What are you doing?’”

Managing Self-Perceptions. Participants also manage their perceptions of themselves by (a) refusing or underutilizing accommodations, (b) finding their place, and (c) embracing their autism. Of concern to participants is how they perceive themselves and maintain their dignity, which sometimes leads them to refuse or underutilize accommodations. Curtis simply stated: “I try to always figure things out by myself.” Like Curtis, Julian also declines accommodations: “I know there are resources on campus. I feel like I can’t utilize them because utilizing them makes me less. Which isn’t true for everyone, I just have that weird complex in my own brain.” Mason acknowledges that underutilizing note-taking services affects his ability to learn: “I get notes posted for me, but honestly, I don’t look at it that much. I probably should, but that just goes with being a normal kid. I try to do everything on my own.” Although refusing or underutilizing accommodations may hinder their learning, participants like Raymond believe

they are preparing for everyday life after graduating: “I’m just trying to prepare myself for when I’m an adult. At least I’ll be able to do things normally.”

Along with refusing or underutilizing accommodations, participants strive for acceptance by finding their place. Participants like Julian do not perceive that they belong on-campus: “I feel disconnected from campus sometimes . . . It feels like people don’t attempt to include autistic people in their considerations of events. And sometimes, it’s just difficult to exist on campus.” To find belonging, participants become involved in on-campus organizations. For instance, Rory’s friends invited them to visit [an identity-affirming organization]: “I met a lot of cool people there, which was interesting, because, normally, if I were to [talk inappropriately] in one of my classes, people would be like, ‘Shut up. Stop talking,’ or people would tell me to leave the room. I don’t know what it is about the people that I’ve met there, but they seem to be more open and understanding.” The organization’s members not only foster belonging, but its physical space also helps reduce Sarah’s overstimulation: “I like hanging out there because they have nice couches and a lot of blankets.” Additionally, building relationships with peers on the autism spectrum helps participants find their place. Julian elaborated on their friendships:

Without my friends, I don’t really have a safe space where I can unmask and be visually autistic and not be worried, because a lot of my other friends are also autistic. Nobody’s going to look at me weird if I touch a weird texture and shake my hands. Or nobody’s going to look at me weird because I’m not looking at them. We’re not looking at each other and we still love each other. And I’ll be over here in my corner doing this, not looking at them, and they’re over there in their corner doing that, not looking at me, and we’re doing great . . . Without that, I would feel 100 times more alone in my life.

Ultimately, participants discussed how they have embraced their autism. Like other participants, Jayme shared how their self-efficacy has improved since

receiving their diagnosis and implementing accommodations: “I’ve been more confident in myself and my work because I’ve been able to better acknowledge when I am struggling and be able to do something about it. I get accommodations for what I’m struggling with, and I’ve figured out better ways to communicate, and that asking for help is fine.” Whereas Sarah and other participants believe that hyper-focusing on their special interests can be distracting, Gabrielle embraces hers (Figure 6):

If [my special interest] coincides with what I am learning in a classroom, I am absorbing the material and dedicated to that class. If I find what I am reading about or writing about enjoyable, I can do it all day without taking a break, just because of that hyper-fixation. So, that is an advantage that I have, being interested and passionate about what I am learning.

Some participants embrace their autism because of their religious beliefs. Bailey shared about his faith, which is also depicted by a cross in his everyday life map (Figure 7): “I know that God has a plan for me, and everything that happens is for a reason. Like there’s a reason I’m on the spectrum. So, it’s comforting to know that there is a reason for everything about me . . . I might not know what that purpose is, but I know that I have that purpose no matter what.” Depicted in her everyday life map (Figure 8), Opal faces an “everyday fight to love [herself]”:

I love who I am, and I would never want to change that. But sometimes, because I’m so different, I don’t like that. And my brain kind of does this seesaw thing, where it tells me I’m stupid, dumb, and worthless, and cuss words I didn’t want to write down. I’m a devout Catholic, so realizing how unique God made me, enables me to lift the right side so that the left side just gets pushed down into the depths of my mind so it can’t bother me. I

go through this struggle every day, but I've noticed lately that love always wins.

Practicing Self-Care

Practicing self-care involves (a) achieving balance, (b) accepting support, and (c) finding solace. Each information practice was described by 15 participants and depicted in nearly two-thirds of their everyday life maps, suggesting that practicing self-care is essential to their everyday lives. In fact, practicing self-care reduces anxiety for participants like Julian (Figure 9).

Achieving Balance. Participants achieve balance by managing their time spent studying. For example, Rachel utilizes an iPad application to organize their assignments and course materials: "I've created my own digital notebook on Notion. It helps me track everything. I can create objectives for classes. So, it makes sure I'm staying on top of what is happening and understanding as I'm going." Making lists helps participants prioritize their assignments for reducing anxiety. Confirming what he illustrated in his everyday life map (Figure 10), Malcolm shared: "Typically, when I have challenging assignments, I will prioritize which one is most important. For the other one, I'll ask for an extension because that's one of my accommodations." List-making not only aids participants' studying; this practice helps students like Ruby manage their health:

I need to make sure that I eat. I am hypoglycemic, so I must eat every few hours or I get sick. And I can't eat garbage. I must eat healthy foods if I want to maintain [balance]. And I don't function well without a good amount of sleep. I've never been the kind of person that can do an all-nighter. It's not for me. I must have that sleep if I want to function the next day.

Participants also achieve balance by budgeting their time spent socializing with friends. Since socializing exacerbates participants' anxiety, selecting which gatherings to attend is crucial. Bailey's roommates understand this: "I'm introverted, but there are times that I feel like I want to be around people . . .

There are always guys to hang out with, people to go do stuff with. But they also respect when I am feeling anxious, feeling a little overwhelmed when I need to stay in and do my own thing. They're also very respectful of that." Sasha and their roommates even have a shared phrase, "bad vibes," which anyone can express when they prefer alone time:

If we have plans to go to a coffee shop or something, but I don't feel like I have the energy for it, I'll just be like, 'Hey guys, bad vibes today, I can't do it.' And then I can just go into my room, and they'll go on without me . . . Same goes for them too. 'Bad vibes' is our keyword for everything. If it's bad vibes, we just let it go. Everyone uses it . . . It's extra nice for me to have one key word, because a lot of times it's hard for me to communicate what I'm feeling because of the autism. If I have a bad feeling and don't want to socialize, I'm just like, 'Hey guys, bad vibes.' So, it makes it a lot easier.

Accepting Support. Participants also practice self-care by accepting support (e.g., advice, physical assistance) from their personal and institutional support systems. Peers, significant others, and relatives comprise participants' personal support systems. Raymond shared: "Usually, I have somebody that can ask. If I want someone to give me genuine advice, I go to my best friend. If something is more about my future, I go to my parents." For example, Sasha relied on their peer for reducing overstimulation when taking a marine biology course: "I would try to do as much of the in-lab studying as I could without opening the fish jars, and then I would wear multiple masks and then I had a good friend in the class. So, whenever we had to get the fish out of the jars, she would do it. I didn't have to get too close to it, which was nice."

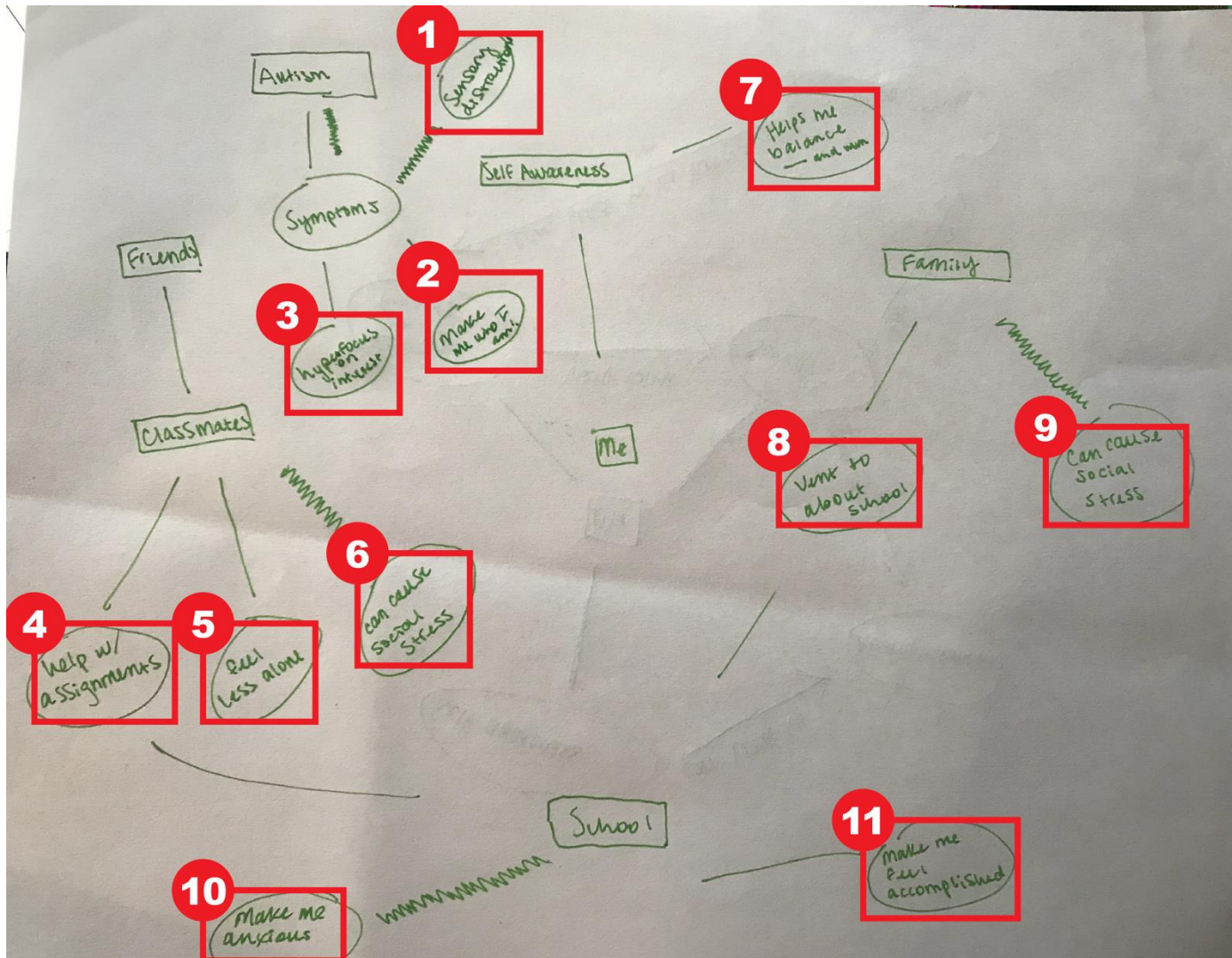


Figure 6. Gabrielle's Everyday Life Map

Codes and Descriptions of Symbols in Everyday Life Map

1. Physical Sensitivity – Distractions in the physical environment can cause anxiety
2. Managing Self-Perceptions – Participant embraces identity as someone on the autism spectrum
3. Managing Self-Perceptions – Hyper-focusing on subjects (e.g., history, humanities) is identity-affirming
4. Working with Peers Versus Working Independently – Studying with participant's peers augments learning
5. Managing Self-Perceptions – Communicating with peers decreases anxiety from being alone
6. Limited Social Awareness – Participant may not realize her peers are taking advantage of her generosity (e.g., sharing homework)
7. Achieving Balance – Reducing participant's anxiety and managing self-perceptions are essential to balancing her academic and everyday demands
8. Accepting Support – Participant's relatives provide emotional support to reduce anxiety
9. Mischaracterizing Autism – Participant's relatives mischaracterize autism, which exacerbates her anxiety
10. Anxiety – Increased workload in higher education prompts anxiety
11. Managing Self-Perceptions – Being able to balance the academic and everyday demands of higher education is satisfying

My Drawing

Participant ID 1102

In this space, please draw an illustration of how you have balanced the academic and everyday demands of being a student over the past year. Consider including any of the following items:

- Challenging assignments
- Technologies used

- Major everyday decisions
- University accommodations used
- Places visited

- Information or resources needed
- Objects used
- Problems faced

- Documents or materials used
- People involved

Do not worry about your artistic ability. Your drawing will be anonymous.

1

2

3

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Participant ID _____

Figure 7. Bailey's Everyday Life Map

Codes and Descriptions of Symbols in Everyday Life Map

1. Finding Solace – Participant's emotional support animal reduces anxiety
2. Managing Self-Perceptions – Participant's Christian religious beliefs affirm his identity as someone with autism
3. Finding Solace – Playing video games helps the participant decrease his anxiety

Participants' significant others also provide support. For instance, Ruby's partner helps them manage their assignments: "My partner helps me keep track of assignments and generally have the courage to bring up what I need, because sometimes I tend to push that aside and avoid it until last minute." Additionally, Rachel's boyfriend and his family helps her build financial literacy: "My boyfriend's family is very good about budgeting. So, I rely a lot on him cause he's very financially responsible. And so, I'll be like, 'Hey, do you think this is a good decision? Or should I buy this?' I will splurge on my special interests. That's okay sometimes, but there's a time and a place for it."

Siblings like Malcolm's brother are supportive, too:

Math and science come easy to me. This is in stark contrast with my brother, who's better at writing than he is at math and science. Things like writing and words come more easily to him than they come to me . . . Typically, once I finish an assignment, he is my editor . . . What I do is, I try to think of more ways to say it and I often end up repeating myself, and then if I'm really struggling, I'll take it to my brother and be like, 'How do I make this longer?

Jayne's sisters helped them gather the information needed to complete assignments for an information science course:

They both did research, so I would ask them for help. I still ask them for help . . . Sometimes it will be like, 'Have you ever used this? What did you do with it?' Right now, I'm taking [a course in government information] and one of my sisters is a lawyer. The other day, I asked, 'What database do you use, or how do you look up information that you need?' And that helps. So, I guess I'm lucky in that regards that I have siblings that I could ask.

Everyday Life Map

Done



My Drawing

Participant ID 305

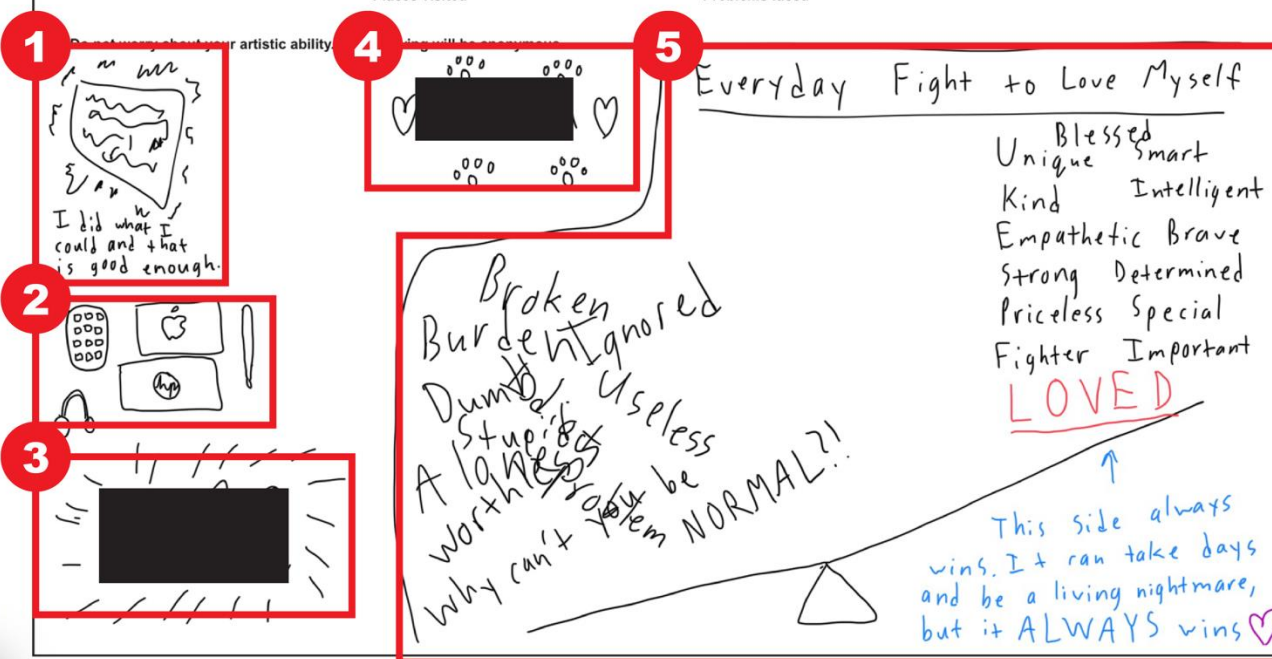
In this space, please draw an illustration of how you have balanced the academic and everyday demands of being a student over the past year.
Consider including any of the following items:

- Challenging assignments
- Technologies used

- Major everyday decisions
- University accommodations used
- Places visited

- Information or resources needed
- Objects used
- Problems faced

- Documents or materials used
- People involved



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Participant ID 305

Figure 8. Opal's Everyday Life Map

Codes and Descriptions of Symbols in Everyday Life Map

1. Anxiety – Increasing workload prompts anxiety
2. Using Study Aids – Participant's phone, laptop, Apple iPad, Apple Pencil, and noise-cancelling headphones facilitate studying (e.g., note-taking, reading, writing) and reduce overstimulation
3. Accepting Support – Participant values the tools received from her institution's disability support services
4. Finding Solace – Participant's service animal alerts her to physiological distress and performs deep touch pressure therapy to reduce anxiety
5. Managing Self-Perceptions – Participant regularly struggles with her identity as being on the autism spectrum (e.g., mischaracterizations, symptoms), yet her Christian religious beliefs help affirm her self-concept

My Drawing

Participant ID 1104

In this space, please draw an illustration of how you have balanced the academic and everyday demands of being a student over the past year.

Consider including any of the following items:

- Challenging assignments
- Major everyday decisions
- Information or resources needed
- Documents or materials used

- Technologies used
- University accommodations used
- Objects used
- People involved

- Places visited
- Problems faced

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Participant ID 1104

Figure 9. Julian's Everyday Life Map

Codes and Descriptions of Symbols in Everyday Life Map

1. Accepting Support – Participant receives help from disability support services, friends, and relatives
2. Anxiety – Having to manage others' perceptions and balance everyday demands increases anxiety
3. Achieving Balance – Participant strives daily to reduce anxiety so balance can be achieved

Beyond their peers, significant others, and siblings, participants rely heavily on their parents, particularly their mothers. Rory prefers talking to their mother: “Honestly, I feel like I’m way too dependent on [my mother]. If even the slightest thing happens, I’m going to call her first, and not my friends, because my friends have other lives that they’re trying to pursue. So, I feel like I’m too dependent on her and might be kind of a burden to her, but in the end, she’s still an important person to me.” Opal’s mother is also supportive:

Even though I was terrified to come to college because I was afraid that I would fail, [my mother] told me, ‘No, you’re not going to. You can do this, and I’ll be here to help you the whole time.’ So once or twice a week, she comes up to visit me and help me with laundry or cleaning up that I haven’t had time to do because I’ve been busy. We’ll sit and talk for a while, and I’ll tell her about some things I’ve been having trouble with. We text every day, and we just talk, and she is amazingly supportive and really helps me.

Sarah depended on her mother when college began, but unfortunately, her mother since passed away, leaving her to rely on her father:

In my first couple of semesters at college, I had a lot of guidance from my mother to help me figure out how everything had to go. Unfortunately, my mother passed away after a few semesters, so I haven’t had her as a resource. An issue I’ve been running into is with my high-level math classes. My father has not taken that level of math, so he cannot help me, but I do sometimes ask him for assistance for interpreting what an assignment is saying or what he would say is implied in this.

Aside from participants' personal support systems (e.g., peers, significant others, relatives), institutional supports can help them care for themselves. Disability support services, for example, offers accommodations to students with disabilities. Madison described their experience requesting them:

I have a history of getting anxious and missing school, and I have been hospitalized before. So, I was like, 'Hey, I can't do that in college. Can you help me?' So, they said, 'Yes,' and my doctor filled out a form of my diagnosis. So, they gave me accommodations, and that's been helpful. And they gave me priority registration which helped so much because I wasn't anxious about it and knew I could figure out what classes I wanted for a semester.

To learn social cues, Ruby utilizes counseling services provided by their institution: "I did therapy with the counseling center, and one of the biggest things that we worked on was interpersonal relationships and asking for help, which was always very difficult for me. But it changed my perspective." Similarly, Justice participates in a specialized program for students on the autism spectrum, which helps them practice self-care:

I have two sessions, my first one is a one-on-one counselor meeting just to check up, and sometimes we practice social skills, like entering conversations, because I'm already good at exiting. And on Thursday, there is a group session with [a psychologist] and [teaching assistants], and we'll suggest something we want to work on. Somebody suggested interview skills once – also, relationships, friendships, and parties. Also, study skills, because I never learned how to study in high school. Do you know those smart kids that could get by? I was one of those in high school, and college will kick a lot of their rear ends at first . . . Dr. [redacted] and her graduate teaching

assistants, they're all nice and have provided a little support network for me. Sometimes I don't have great ideas, sometimes they're rushed, I didn't think about them, so it helps to talk things out with other people.

Finding Solace. Finally, participants practice self-care by finding solace. Studying in quiet places, retreating to sensory spaces, and depending on service animals are ways that participants find solace. Like other participants, Raymond prefers studying in their bedrooms, which helps reduce overstimulation: “[Studying in a public place] might help me concentrate more, but I just like working with no one around. You don't have to focus on being appropriate or anything. For example, if I was in a library, I probably wouldn't be listening to music super loudly, but I can do that in my residence hall because nobody's there.” Mason keeps his bedroom clean to maintain focus: “I like when things are clean. It must be the right setting. I don't like doing my work in a messy room. So, my room, for the most part, is clean. I make my bed, so I feel comfortable.”

Outside their homes, participants like Ruby sometimes find quiet places to study in their academic libraries: “Lately, I've been going to the [academic library's name], which is on the [satellite] campus. It's smaller and quiet there. They don't get loud and boisterous, and there's this one spot in the corner. It has a cool, 'futuristic' chair. I like to sit there, put a rolling table over my lap, and use my iPad.” Curtis even has a private study carrel: “I do have one that has a nice view of [downtown]. Also, being able to get a whiteboard and put that on the other side of me gives me my own little box.” While studying, participants listen to music to help prevent overstimulation and maintain their focus. Listening to music is largely represented in Jayme's everyday life map (Figure 11). In fact, Jayme shared during their interview: “I can listen to music or podcasts while I [study], which is nice because my special interest is music. I feel like I'm more productive when I have that sound because it's a controlled sound instead of not.”

My Drawing

Participant ID 301

In this space, please draw an illustration of how you have balanced the academic and everyday demands of being a student over the past year. Consider including any of the following items:

- Challenging assignments
- Technologies used

- Major everyday decisions
- University accommodations used
- Places visited

- Information or resources needed
- Objects used
- Problems faced

- Documents or materials used
- People involved

Do not worry about your artistic ability. Your drawing will be anonymous.

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graph TD
    1[Challenging Assignments] --- 2[Prioritizing]
    1 --- 3[Extra time]
    1 --- 4[Accommodations]
    1 --- 6[Alternative Testing]
    1 --- 8[Satisfaction of Completing Them]
    2 --- 5[Problems Faced]
    3 --- 4
    3 --- 6
    3 --- 8
    4 --- 6
    5 --- 7[Deadlines]
    5 --- 8
    6 --- 8
    7 --- 8
  
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Participant ID 301

Figure 10. Malcolm's Everyday Life Map

Codes and Descriptions of Symbols in Everyday Life Map

1. Anxiety – Having to complete challenging assignments increases participant's anxiety
2. Achieving Balance – Participant prioritizes which assignments are most important
3. Accepting Support – Receiving additional time on assignments helps achieve balance
4. Accepting Support – Accommodations received from disability support services are helpful for prioritizing assignments and managing anxiety
5. Anxiety – Having to prioritize assignments heightens participant's anxiety
6. Accepting Support – Alternative testing accommodations help reduce anxiety
7. Anxiety – Increased workload and looming deadlines prompt anxiety
8. Managing Self-Perceptions – Completing assignments is satisfying

Finding solace is not limited to studying or listening to music in quiet places. Retreating to sensory spaces helps participants like Sasha reduce overstimulation (Figure 12): “The gray thing, it looks like a shower, but it’s not, it’s my nook. I have a little corner in my room with a bunch of soft, sensory-friendly things and stuffed animals, and there’s a curtain so I can close myself in. And then, I have buckets of beans for sensory stimulating.”

Ultimately, service animals can reduce participants’ anxiety and overstimulation. Opal introduced me to [name redacted], her service dog:

[Name redacted] helps me with [social interactions] because they spike my anxiety. I used to avoid interactions, but now if I have a panic attack, or I get overwhelmed and go into a sensory meltdown, [name] is there to help me with deep pressure therapy, grounding me and letting me know he’s there, helping calm me down. That helps knowing that I have him with me and that if things don’t go well, he’ll be there, and that’s made me happier and improved my social life.

Recommendations for Providing Structural Agency

During the interviews, I asked participants for recommendations to provide structural agency. Participants believe their institutions should (a) design accessible instruction, (b) reduce mischaracterizations, and (c) enhance functioning (Table 7). I offer illustrations of participants’ recommendations.

Design Accessible Instruction

To design accessible instruction, professors should (a) provide explicit instructions and “spoon-feed,” (b) make information accessible, and (c) promote hands-on learning.

Provide Explicit Instructions and “Spoon-Feed”. Participants like Mason believe their professors must provide explicit instructions: “Things must be straightforward. That’s usually how it goes for kid on the spectrum. If things are straightforward, it’s pretty much easier. Sometimes if it gets a little more in detail, it’s a lot harder for someone on the spectrum.” Madison expressed the

need for explicit instructions: “I need specific, clear expectations. And they don’t really tell you that. It says it in the syllabus, but they never really elaborate on it. I love my teacher so much. She’s so flexible, but I need to be told, ‘This is what you’re supposed to do.’ She leaves it up to you.” For Justice’s parents, professors who remind their students about deadlines are “spoon-feeding”:

My parents always call this spoon-feeding, but I’d like professors to give more reminders about deadlines because I will simply forget. Usually, professors just say it once, it’s on the syllabus, and that’s all there is to it. Nothing until it’s due. And that doesn’t work for me as somebody with autism.

Make Information Accessible. Another means of designing accessible instruction is making information accessible. Professors can accomplish this recommendation by recording lectures. Bailey shared how recordings compensate for his anxiety: “Recorded lectures across the board would be beneficial. Many professors post their slides and speaker notes, but if I miss class because I have a panic attack, looking at slides and reading speaker notes doesn’t have the same effect as if I was in that class. The closest way to replicate that would be to have a video of that lecture.” Recordings also aid participants’ information-processing, as Justice described: “Because of autism, I have some auditory and information-processing difficulties. So going back and watching the lecture so the teacher doesn’t have to repeat themselves, and I can listen to it repeatedly, is so helpful.” Aside from consuming recordings, captions enhance information-processing. Rory described: “Having [captions] helps me to engage more. Sometimes, there are things that happen in my environment that’ll distract me, and then I’ll come back and be like, ‘Whoa, what’s going on?’ It’s not that I can’t hear. It’s more of a focus thing, tuning out the environment.”

Promote Hands-On Learning. Promoting hands-on learning is another recommendation participants offered for designing accessible instruction. Participants like Rory believe that traditional assessments (e.g., examinations, papers) fail to capture what they learn:

Honestly, I hate sitting down and taking a test. That is not a good way to show how much you have gained from the class. If you get a question wrong, you could still know how to answer the question. It's just that question might have been a bit hard, or maybe you misread the question. When teachers are grading, they're like, 'Oh, this person doesn't know this because they got the question wrong.' It would be more inclusive to sit down and do something more creative than answer some questions on a piece of paper.

Rachel added that gaining field experience would better prepare her for employment than completing traditional assessments:

I wish college were less based on memorization ability and more on my capability to do the job that I'm working towards – getting out into the field and doing what I'm supposed to do. And I have a lot of field experience, but I still struggle immensely with memorization. So, I wish my grade could be based less on memorization and more on my genuine abilities.

Reduce Mischaracterizations

Providing structural agency to students with autism is not limited to accessible instructional design. Participants in this study believe that their institutions should reduce mischaracterizations of autism in several ways: (a) form community partnerships, (b) inspire autism allies, and (c) promote accessible events.

Form Community Partnerships. Participants believe that their institutions should partner with community organizations that serve people with autism. Raymond spoke about reducing mischaracterizations by engaging providers of early intervention services to children on the autism spectrum:

I think [the university] should talk more to the [redacted] community and kids with autism. Early intervention is the most

important thing, and if we do that, I think there could be someone else like me out there. I don't know if there's anyone else out there like me. I'm sure hoping there is. I'm sure there is, but they're pretty much hidden, like me.

Gabrielle volunteers with an autism advocacy organization, which partners with [a local aquarium] to host "Sensory-Friendly Days" for children and their families: "Probably once every couple of months, they'll turn off the lights and extra music that's in the aquarium, and they open the aquarium two hours early so families with kids on the spectrum can show up in a quieter, way less crowded environment and still get to go to the aquarium." Similarly, Bailey's fraternity volunteers for a disability advocacy organization, which serves students with disabilities: "I am likely to be our [fraternity's] next service coordinator, and if I get that position, [the university's relationship with the organization] is something that I will maintain. I think [redacted], and how the university supports it, is excellent. Not just for students on the autism spectrum but any students with disabilities."

Inspire Autism Allies. Raising awareness of autism spectrum disorder for reducing mischaracterizations is important to participants. Opal described her institution's "Now You See Me" campaign:

Just because it's invisible doesn't mean it's not there . . . So, [disability support services] is doing a campaign, they did this last semester, on invisible disabilities. They gave out these t-shirts. I haven't worn mine yet, but it says, 'Now You See Me' . . . When people wear the shirts, it shows that you can have a disability and you won't look disabled. But just because you can't see it, doesn't mean it's not there.

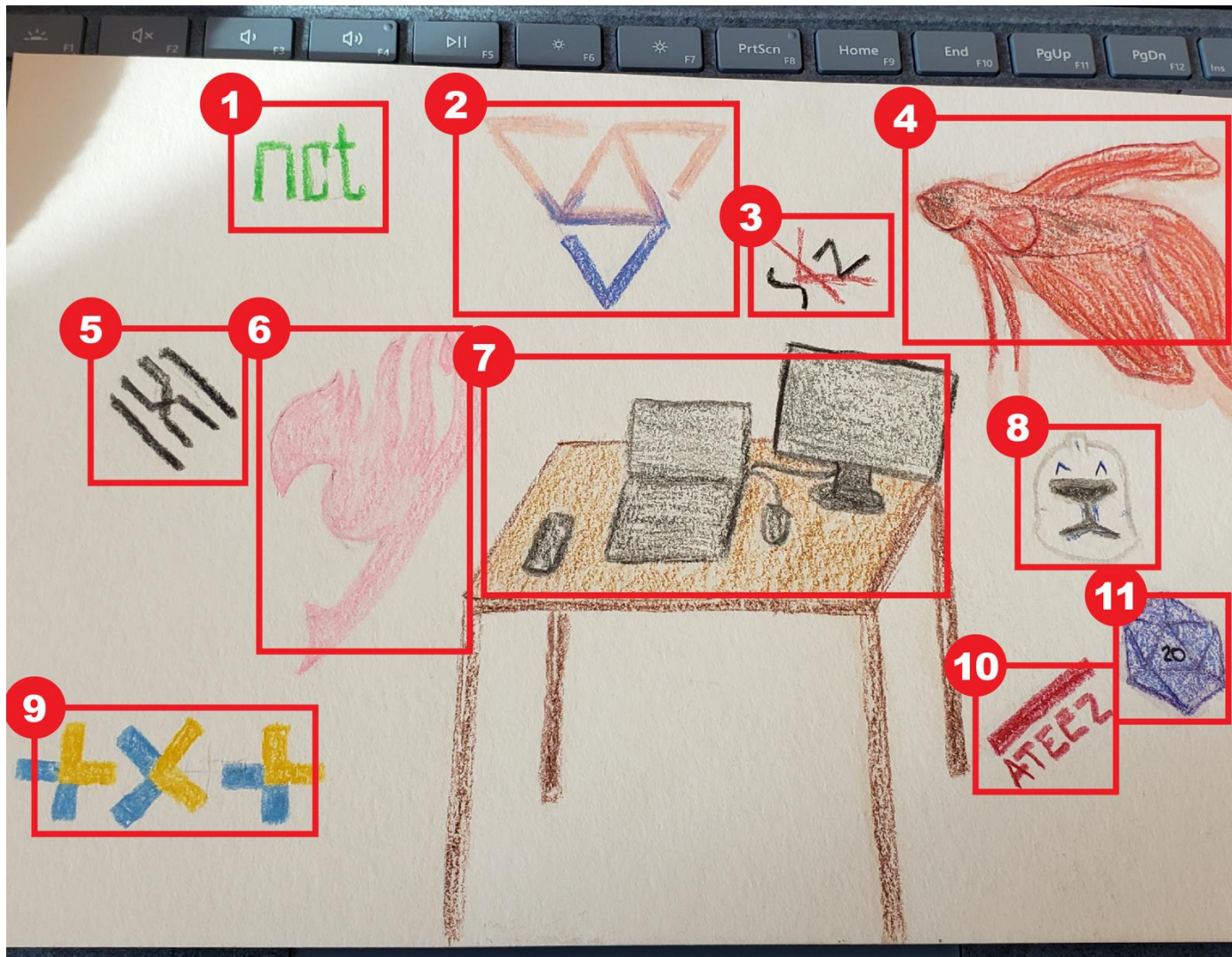


Figure 11. Jayme's Everyday Life Map

Codes and Descriptions of Symbols in Everyday Life Map

1. Finding Solace – K-Pop musical artist, part of the participant's "Cozy Café" playlist, helps reduce anxiety
2. Finding Solace – K-Pop musical artist helps reduce participant's anxiety
3. Finding Solace – K-Pop musical artist helps reduce participant's anxiety
4. Finding Solace – Participant's betta fish brings comfort and reduces anxiety
5. Finding Solace – K-Pop musical artist helps reduce participant's anxiety
6. Finding Solace – Watching anime television series decreases anxiety
7. Using Study Aids – Participant's desk and computer workstation with secondary monitor ease studying
8. Finding Solace – Watching Star Wars movies suppresses participant's anxiety
9. Finding Solace – K-Pop musical artist helps reduce participant's anxiety
10. Finding Solace – K-Pop musical artist helps reduce participant's anxiety
11. Finding Solace – Playing Pathfinder games lessen anxiety

Table 6. Participants' Information Practices

Information Practices (Axial Codes)	Features (Initial Codes)	Participants (Frequency)
Learning	Using Study Aids	<i>n</i> = 15 (94%)
	Working with Peers Versus Working Independently	<i>n</i> = 11 (69%)
	Consulting Professors	<i>n</i> = 8 (50%)
	Receiving Tutoring	<i>n</i> = 7 (44%)
Building Life Skills	"Panic Researching" for Living Independently	<i>n</i> = 6 (38%)
	Researching Careers	<i>n</i> = 5 (31%)
	Becoming Financially Literate	<i>n</i> = 1 (6%)
Managing Perceptions	Managing Others' Perceptions	<i>n</i> = 14 (88%)
	Managing Self-Perceptions	<i>n</i> = 12 (75%)
Practicing Self-Care	Achieving Balance	<i>n</i> = 15 (94%)
	Accepting Support	<i>n</i> = 15 (94%)
	Finding Solace	<i>n</i> = 15 (94%)

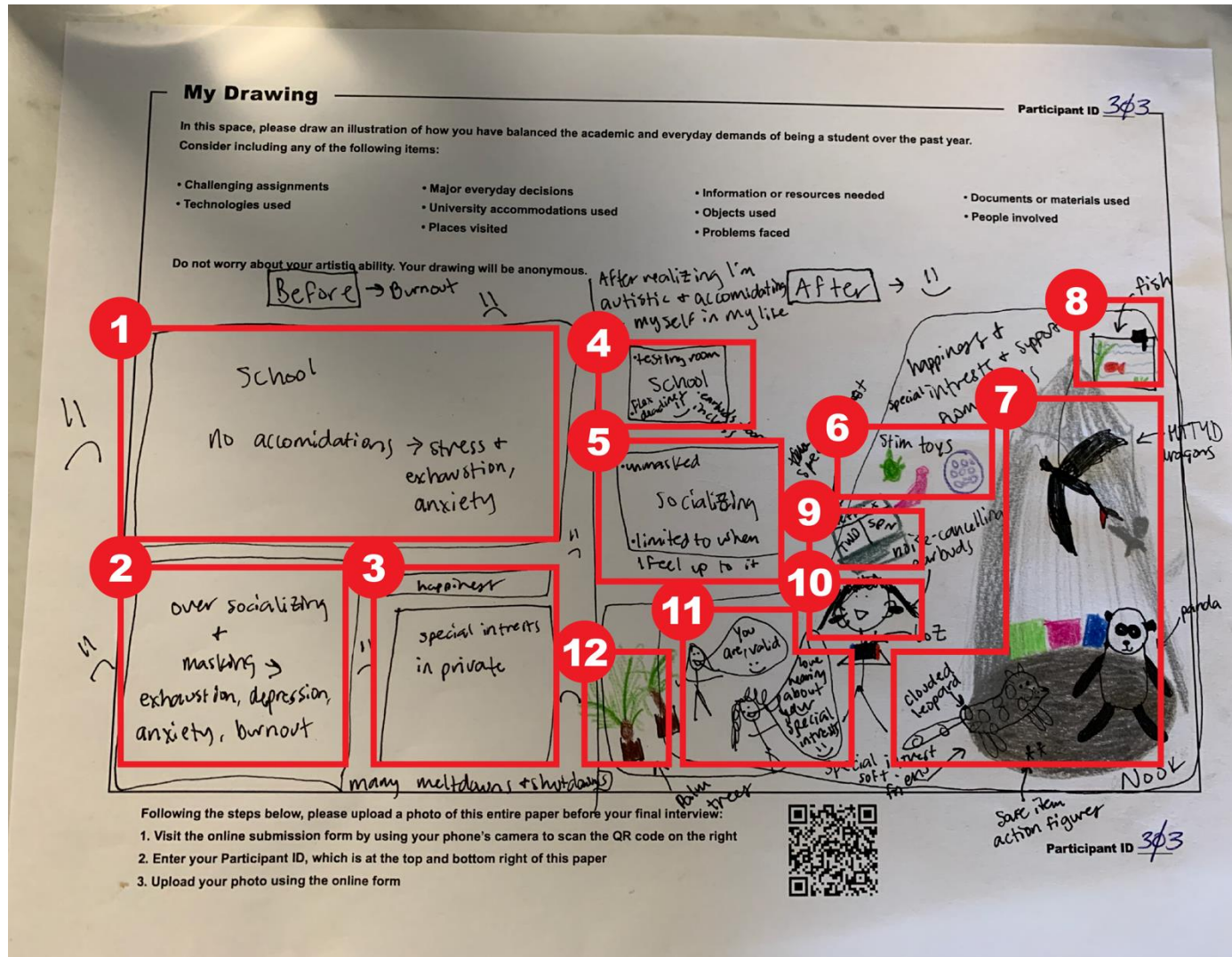


Figure 12. Sasha's Everyday Life Map

Codes and Descriptions of Symbols in Everyday Life Map

1. Anxiety – Before receiving their autism diagnosis, participant was anxious
2. Managing Others' Perceptions – Participant used to mask around their peers, which exacerbated anxiety
3. Managing Self-Perceptions – Participant used to conceal their autism, particularly their special interests
4. Accepting Support – Since receiving their diagnosis, participant gladly receives tools (e.g., accommodations, assistive technologies) from their institution's disability support services
5. Achieving Balance – Participant now carefully plans their time, including the amount of time spent socializing with friends
6. Finding Solace – Sensory tools, such as stimming toys (e.g., turtle stuffed animal, bucket of beans), help reduce anxiety
7. Finding Solace – Participant's room includes a "nook," which has blankets, sensory tools, and their special interests (e.g., dragons, stuffed panda bear, clouded leopard, The Walking Dead action figure)
8. Finding Solace – Participant's fish help reduce anxiety
9. Finding Solace – Watching television shows such as The Walking Dead help decrease participant's anxiety
10. Finding Solace – Using noise-cancelling earbuds decreases anxiety from overstimulation
11. Managing Self-Perceptions – Participant's roommates affirm their identities and make them feel valued
12. Finding Solace – Palm trees bring the participant comfort

Similarly, Sasha's institution hosts an awareness campaign:

I recently joined [organization's name redacted]. We talk about accessibility and advocacy, either advocating for other people or advocating for yourself. And they also have events. This week, they have a table set up in the library all week for the "R-Word Campaign" to raise awareness that the word is a slur and should not be used.

Those campaigns are initiatives designed not only to raise awareness of autism spectrum disorder, but over time, can inspire people across institutions to become autism allies. Jayme stated: "I don't know if they do it here, but if they have a sticker on their window, they're an ally. They go to a training session. I'm like, 'You could do that with autism, too.'"

Promote Accessible Events. Promoting accessible events can help members of the autism community find acceptance. Gatherings of students with disabilities, particularly those with psychosocial barriers, is valuable for participants like Bailey: "I think that is invaluable, because sure, I could sit in my room alone all day and only do schoolwork, but I'd go crazy. And so, making it easier for people with disabilities to get involved, to find their people, would be excellent. I think that'd be a perfect way to help people." Beyond attending accessible events, students on the autism spectrum may form relationships with their peers. Gabrielle shared with me: "A huge thing is being friends with people who know what's going on, or you're able to laugh about it with them. So, from a university standpoint, put students on the spectrum in contact with other students who can support them."

Enhance Functioning

Participants also recommended that their institutions enhance students' functioning. To enhance functioning, institutions can (a) improve disability support services, (b) create sensory spaces, and (c) provide life skills training.

Improve Disability Support Services. To enhance students' functioning, institutions can improve disability support services. Participants like Malcolm

shared that disability support services should explicitly publicize the tools they provide (e.g., accommodations, assistive technologies) to students with autism:

Another thing the university could do to better support students on the spectrum is to be upfront about how [disability support services] can offer accommodations, and how to request accommodations. Because, when I was going through that process, requesting accommodations, and receiving them, was something my family and I had to find on our own.

Streamlining the process for requesting accommodations and assistive technologies would be beneficial, according to participants. In fact, requesting tools prompts anxiety for participants, as Ruby shared: “The experience made me anxious because I had to talk to a bunch of people, make a lot of phone calls, which I don’t like doing, and send a lot of emails. It was difficult to get in contact with [my coordinator].”

Participants like Malcolm even recommended the establishment of a specialized, autism-friendly unit within disability support services:

One thing that I think the university could do to better support students on the spectrum is to have a separate office within [disability support services], that is more specialized for students on the spectrum . . . People working there would have more experience dealing with people on the spectrum than with people with general disabilities . . . One way to make it more relatable would be to have employees who are on the spectrum.

Ultimately, disability support services can improve by making diagnostic testing freely available to students who report academic and social challenges. Sasha’s testing to receive their diagnosis was expensive:

I had to pay \$500.00 for testing, and that was half the price of other options. Maybe universities could offer cheaper or free testing for students. That might be nice, because many people

don't have \$500.00—2,000.00 to spend on testing . . . I think it would be nice for universities to be aware of the difficulties getting a formal diagnosis and have some avenue of helping students who can't get one.

Create Sensory Spaces. Reflected in Madison's everyday life map (Figure 13), participants recommended creating sensory spaces which can help students reduce overstimulation and find solace. Curtis shared: "Maybe a quiet, isolated place would be nice. Because that's where I feel I excel. It could be a small room in an academic building, or the library, or a big room that's been split into rooms."

Provide Life Skills Training. Institutions like Justice's provide life skills training (e.g., budgeting finances, managing schedules, preparing meals) to students with autism, however, the programs can be expensive: "I'd like to say that the university is doing something good with the [name redacted] program, though I do feel like it could be less expensive for people that need it, for some reason, they couldn't get the state to pay for it." Participants like Rachel believe their institutions can provide more accessible training, such as financial literacy education: "I would love to see some sort of one-credit-hour financial literacy class, something to teach you about getting a credit card, and when you should get a credit card . . . That would be very beneficial, especially for people who are disabled and living on their own now. That's very much missing."

Significance of the Everyday Life Maps

Participants' interviews and everyday life maps featured similarities and differences. First, practicing self-care (e.g., achieving balance, accepting support, finding solace) was highlighted across participants' interviews and illustrations (i.e., 15 of 16 participants). Second, although participants talked during the interviews about working with their peers (i.e., 11 of 16 participants), they seldom drew their peers in the everyday life maps (i.e., 2 of 13 drawings). Third, participants' study aids (e.g., mobile applications, tablets, assistive technologies) were largely described during the interviews (i.e., 15 of 16 participants), but those

tools were less often depicted in participants' everyday life maps (i.e., 3 of 13 drawings). Finally, participants' interviews emphasized ways they manage others' perceptions (e.g., masking) (i.e., 14 of 16 participants), whereas participants' drawings highlighted their self-perceptions (e.g., embracing their autism) (i.e., 7 of 13 drawings). Altogether, these findings suggest that although participants were comfortable talking about their desire for independence and normality (e.g., learning, building life skills, masking), they relied on their drawings to critique their higher education institutions (e.g., mischaracterizations of autism, inaccessible social gatherings).

Theoretical Coding

After analyzing participants' data during multiple rounds of initial and axial coding, I used theoretical coding to answer my overarching RQ: *How can a higher education institution provide structural agency to autistic students engaged in their everyday information practices?* Consistent with GTM, I organized the axial codes into themes (Charmaz, 2014). Themes included identity and well-being (Table 8). Using those themes as search criteria, I reviewed literature to identify theories that incorporate my axial codes.

Theoretical coding helped me uncover sensory and social well-being. Sensory well-being “. . . requires an understanding of how people with sensory-processing issues experience the world differently, primarily through sight, touch, and hearing” (Essary et al., 2020, p. 82). Social well-being is defined as “. . . the appraisal of one's circumstance and functioning in society” (Keyes, 1998, p. 122). Sensory well-being contributes to social well-being since the latter theory incorporates sensory functioning. Together, theoretical constructs of sensory and social well-being include (a) structural agency, (b) personal support systems, (c) everyday information practices, (d) optimal functioning, and (e) belonging. In Chapter Five, I propose a model of sensory and social well-being and apply these constructs to the findings.

Table 7. Participants' Recommendations for Providing Structural Agency

Recommendations (Axial Codes)	Features (Initial Codes)	Participants (Frequency)
Design Accessible Instruction	Provide Explicit Instructions and "Spoon-Feed"	<i>n</i> = 6 (38%)
	Make Information Accessible	<i>n</i> = 5 (31%)
	Promote Hands-On Learning	<i>n</i> = 4 (25%)
Reduce Mischaracterizations	Form Community Partnerships	<i>n</i> = 4 (25%)
	Inspire Autism Allies	<i>n</i> = 4 (25%)
	Promote Accessible Events	<i>n</i> = 2 (13%)
Enhance Functioning	Improve Disability Support Services	<i>n</i> = 4 (25%)
	Create Sensory Spaces	<i>n</i> = 2 (13%)
	Provide Life Skills Training	<i>n</i> = 2 (13%)

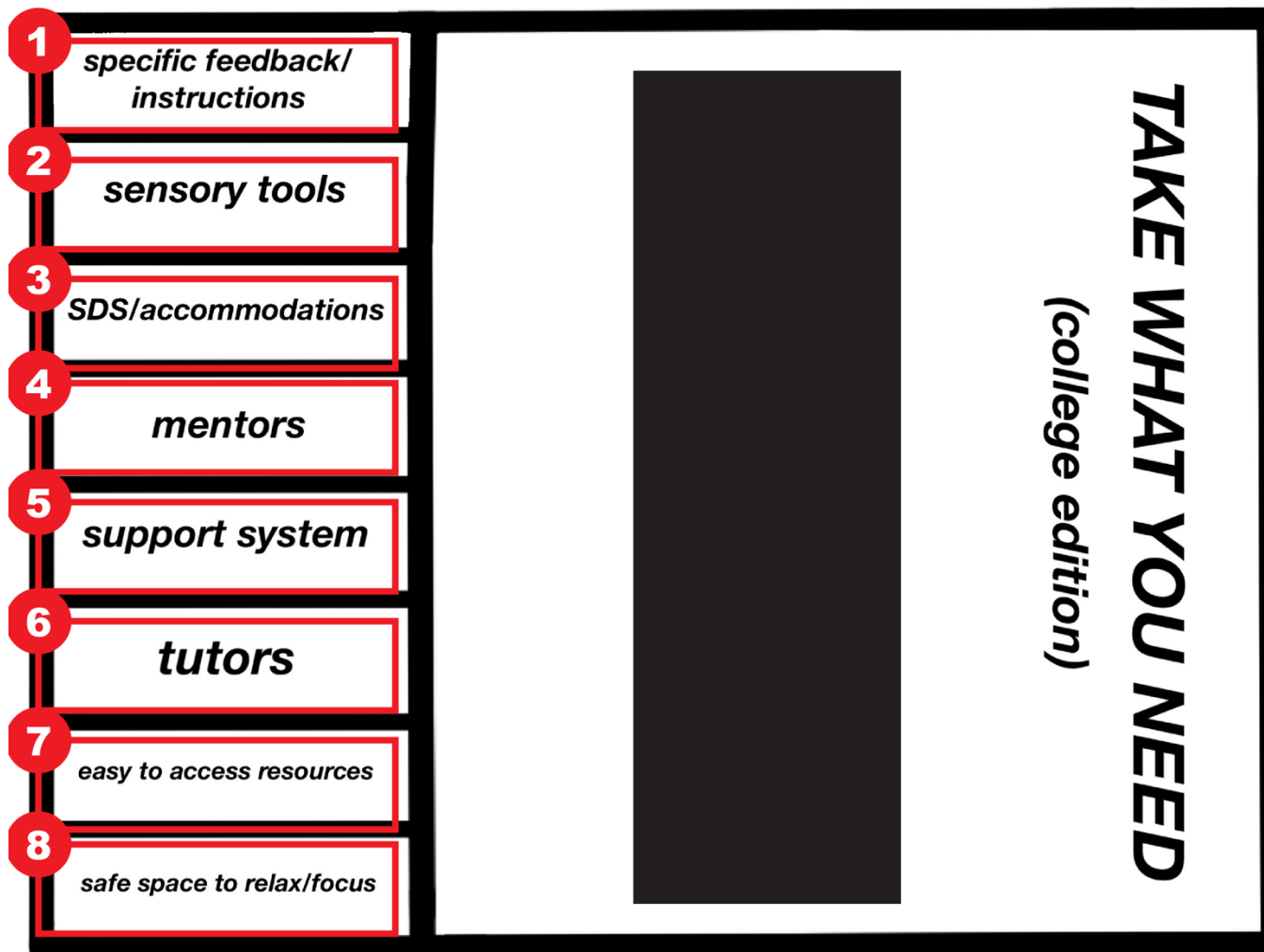


Figure 13. Madison's Everyday Life Map

Codes and Descriptions of Symbols in Everyday Life Map

1. Provide Explicit Instructions and “Spoon-Feed” – Professors should provide students with specific feedback
2. Finding Solace – Sensory tools, such as fidget objects, weighted blankets, relaxing music, and noise-cancelling headphones, are ways to reduce anxiety
3. Accepting Support – Disability support services provide accommodations, such as alternative testing locations and housing accommodations (e.g., private rooms)
4. Inspire Autism Allies – Mentors should include peer mentors, resident advisers, and academic advisers
5. Accepting Support – Personal support system includes relatives, friends, and healthcare providers (e.g., counselor, psychiatrist)
6. Receiving Tutoring – Tutors help the participant study
7. Improve Disability Support Services – Accommodations for autistic students should be more accessible
8. Create Sensory Spaces – Creating sensory spaces helps students with autism reduce anxiety

Table 8. Themes Comprising Axial Codes

Themes	Axial Codes
Identity	Ableism Managing Perceptions Reduce Mischaracterizations
Well-Being	Building Life Skills Design Accessible Instruction Enhance Functioning Learning Overstimulation Practicing Self-Care Psychosocial Barriers

CHAPTER FIVE: DISCUSSION AND CONCLUSION

Chapter Five discusses the findings' theoretical, practical, and methodological implications and their limitations. Ultimately, I offer recommendations for future research and share final thoughts.

Proposed Model of Sensory and Social Well-Being

Utilizing the constructs of (a) structural agency, (b) personal support systems, (c) everyday information practices, (d) optimal functioning, and (e) belonging, I propose and apply a theoretical model of sensory and social well-being (Figure 14).

The first theoretical relationship depicted in this model connects participants' personal support systems (e.g., relatives, significant others, friends) and their everyday information practices. Participants depend on their relatives to seek, use, and share information (Anderson & Butt, 2017; Cullen, 2015). For example, if Jayme is challenged when seeking information to complete assignments, their sisters recommend digital libraries and help Jayme identify credible publications. Other information participants receive include campus directions, dining hall hours, and important announcements (LeGary, 2017). Participants' siblings, parents, and significant others also assist them with using information. Among other examples, Malcolm's brother proofreads writing assignments, and Bailey's parents help interpret the symbolism in readings. Participants' significant others even help them manage projects (e.g., clarifying instructions, meeting deadlines). Beyond academics, Rachel's boyfriend helps create and maintain budgets to promote responsible spending. Furthermore, participants regularly share other everyday concerns (e.g., managing healthcare, navigating relational conflicts) with relatives, significant others, and friends, who offer advice for addressing those challenges.

The second relationship illustrated in the proposed model shows the effects of structural agency provided by institutions (e.g., people, information, norms, tools) on participants' everyday information practices. Institutions are

positioned to better facilitate autistic students' information-seeking. Disability support services, for example, should make information about diagnostic testing and tools (e.g., accommodations, assistive technologies) more accessible. Institutions could also provide easier access to information regarding healthcare resources (e.g., counseling services and medical insurance plans). Additionally, institutions can better support autistic students' learning. For instance, professors should provide explicit instructions for assignments (e.g., examples, rubrics, step-by-step directions), deliver materials in alternative formats (e.g., captions, recordings), promote hands-on learning (e.g., fieldwork, presentations), and fully implement accommodations and assistive technologies. Collectively, these practices can augment autistic students' information-processing while reducing their anxiety. Lastly, to strengthen information-sharing among autistic students and their neurotypical peers, institutions should plan accessible events. Social gatherings can encourage communication; educate neurotypical professors, staff members, and students about neurodiversity; and inspire everyone to reduce mischaracterizations of autism.

The third theoretical relationship present in the model highlights the influence of participants' everyday information practices on their optimal functioning (e.g., learning, managing perceptions, practicing self-care, and building life skills). Participants seek, use, and share information in various contexts to learn. For example, participants seek clarification from their professors when expectations for assignments are unclear (Singh et al., 2020). In addition, participants search for details via scholarly websites and supplemental videos to better understand their learning. Using information consists of receiving tutoring (O'Neill et al., 2012) and employing study aids (e.g., mobile applications, tablets, assistive technologies), among other activities. Finally, sharing information with peers (e.g., knowledge, materials) helps participants learn and bolsters accountability. Collectively, participants' information practices for learning enable them to master the required knowledge and build essential skills.

Aside from learning, participants' information practices also influence how they manage perceptions (e.g., others' perceptions, self-perceptions). Neurotypical people's attitudes toward autism can be misguided and discriminatory (Griful-Freixenet et al., 2017). For example, peers who mischaracterize participants with autism as aggressive hesitate to include them in academic and social settings (White et al., 2019). Confronting these mischaracterizations, participants engage in perception management and must decide whether to disclose their autism. Numerous participants, for instance, strive to appear normal (e.g., making appropriate eye contact and maintaining coherent conversations) (Huang et al., 2022), and they conceal their autism by using information from websites, videos, and psychology textbooks. Some participants who share their diagnoses may receive disability support services (Evans, 2019), gain acceptance from peers (Brosnan & Mills, 2016), and dispel mischaracterizations of invisible disabilities (Thompson-Ebanks & Jarman, 2018). For example, Rory places pins on their backpack to share their intersecting identities (e.g., autistic, LGBTQ+) with others. Furthermore, by disclosing information about themselves, participants may be invited to join identity-affirming organizations (e.g., disability advocacy groups, LGBTQ+ organizations, religious groups), which reinforce their self-perceptions.

Additionally, participants' everyday information practices affect how they practice self-care (e.g., achieving balance, accepting support, finding solace). When studying, for example, participants research quiet, isolated places. To avoid feeling overstimulated, participants monitor their physiological responses to stimuli (e.g., crowds, noises, weather) and decide when to isolate themselves from their peers. Managing schedules, another means of using information, help participants balance academic and everyday demands (e.g., studying, eating, napping, socializing). When participants encounter physiological distress, their emotional support animals alert them to that sensory information so they can promptly engage in self-therapy, such as breathing exercises and deep pressure therapy. Participants even use sensory tools (e.g., fidget objects, sensory

blankets) to avoid subsequent panic attacks (Thompson-Ebanks & Jarman, 2018). Finally, sharing information for practicing self-care includes telling friends when they are exhausted. Sasha's roommates use a shared phrase, "bad vibes," to indicate their need for isolation.

Furthermore, participants' information practices shape how they build life skills (e.g., researching careers, living independently, building financial literacy). Building life skills is essential for mastering everyday life (Kim & Baker, 2021). Participants learn about exciting careers, for instance, by gathering information from websites and videos. Engaging in "panic researching" for finding accessible housing (e.g., comparing costs, identifying transportation) is another way participants seek information to build life skills. In addition, participants like Sasha learned about autism by finding information online (e.g., websites, TikTok videos) and then received formal diagnoses from specialists. Finally, banking applications and digital notebooks help participants avoid excessive spending on special interests (e.g., comic books, video games) and build financial literacy.

Ultimately, participants' optimal functioning contributes to their belonging and sensory and social well-being. Designing accessible instruction, for instance, can make higher education curricula inclusive for all students, with and without disabilities (Meyer et al., 2014). Also, hosting accessible events can help reduce neurotypical peers' mischaracterizations of autism, which is crucial to increasing belonging (Mazumder & Thompson-Hodgetts, 2019). Further, assisting students on the autism spectrum in identifying valuable tools (e.g., accommodations, assistive technologies) can bolster belonging (Potnis & Mallary, Forthcoming). Even providing life skills training (e.g., budgeting finances, communicating interpersonally, managing schedules) to every student increase belonging (Francis et al., 2019). Those participants who perceive they belong spend less time concealing their identities, which reduces their anxiety (Cage & Troxell-Whitman, 2020).

Theoretical Implications

Findings from this study have several theoretical implications. First, whereas people's sensory experiences can aid their everyday information practices (Hartel, 2019; Olsson & Lloyd, 2017), participants reported that physical sensitivity and crowding, features of overstimulation, impede their self-care (e.g., achieving balance, finding solace). They find their classrooms, residences, and academic libraries noisy and crowded, which impede their information-processing (e.g., note-taking, studying) (Everhart & Anderson, 2020). Contrary to previous studies of embodied information practices, participants' overstimulation suggests that sensory experiences are not always helpful.

Second, although participants made recommendations for improving disability support services, most participants could not articulate hypothetical requests. This finding suggests emotional blindness (Baron-Cohen, 1997). Making requests is concerning for people with sensory and social challenges who cannot translate their conscious information needs into formalized ones and receive assistance (Ruthven, 2019). Like Madison shared: "It's difficult to communicate verbally for a lot of autistic people. Every autistic person is different, but it can be tough to reach out. Sometimes, I can't articulate what I need." Consequently, how can students with autism recommend solutions if they cannot communicate their information needs?

Finally, conversations about belonging in the autism and disability literature are increasing (Gibson & Bowen, 2019; Gibson & Martin, 2019; Miller, 2018). The finding that participants learn to control their appearance and speech to avoid exclusion (i.e., masking) contributes to those discussions.

Practical Implications

Institutions are positioned to help students on the autism spectrum learn, manage perceptions, practice self-care, and build life skills. However, institutional constraints, such as ableism and overstimulation, hinder participants' everyday information practices. To enable students with autism to seek, use, and share information for mastering everyday life, higher education institutions should

consider designing accessible instruction, reducing mischaracterizations, and enhancing functioning. Collectively, these initiatives may bolster the sensory and social well-being of students with and without autism.

Design Accessible Instruction

Participants' recommendations for designing accessible instruction – provide explicit instructions and “spoon-feed,” make information accessible, and promote hands-on learning – align with Universal Design for Learning (UDL) (Meyer et al., 2014). For example, professors who provide learners with multiple means of accessing information, engaging with it, and creatively demonstrating their mastery of knowledge and skills, enable all students, regardless of their abilities, to become expert learners (CAST, 2018). As professors learn about and embrace UDL, higher education institutions can shift responsibilities from students' personal support systems to their institutions (Edyburn, 2010).

Reduce Mischaracterizations

To reduce mischaracterizations, higher education institutions can plan sensory-friendly events that include students with and without autism (Ashbaugh et al., 2017). Through these accessible events, autistic students' neurotypical peers can jettison their misguided beliefs about autism. To reiterate Julian's comment, “. . . include us in your conversations and don't leave us out because we exist.”

Enhance Functioning

Higher education institutions are poised to elicit autistic students' information needs, and in turn, augment their sensory and social well-being. Considering my “spoon-feeding” finding, disability support services can improve by better publicizing accommodations and assistive technologies. Since students with autism seldom realize the value of using these tools (e.g., managing self-perceptions, optimal functioning) (Potnis & Mallary, Forthcoming), disability support services could educate them about their potential benefits. Researchers and practitioners could develop a collective resource (i.e., “Autism Toolkit”) that coordinators review with students and select helpful tools.

Institutions can reduce students' dependence on their personal support systems by providing life skills training. Even institutions with specialized programs for students on the autism spectrum rarely offer life skills training (e.g., budgeting finances, communicating interpersonally, managing health) (Viezel et al., 2020). Aside from helping autistic students build financial literacy, disability support services can provide peer-mediated training (e.g., video modeling, role-playing) to help them learn and apply social cues and dress appropriately and maintain personal hygiene (Jamison & Schuttler, 2017). Autistic students may also benefit from learning how to prepare meals and manage their diets (Gustin et al., 2020). Generally, life skills training can help all students, not only those on the autism spectrum (Francis et al., 2019). Hence, institutions could require that all students, no matter their abilities, participate in such training to prepare for everyday life after graduating.

To enhance the sensory and social well-being of students with autism, practitioners can not only implement UDL, host accessible events, raise students' awareness of tools, and provide life skills training. Practitioners should consider additional recommendations:

- Within disability support services, administrators could hire coordinators who are on the autism spectrum, a practice which could reduce mischaracterizations and enhance students' self-perceptions.
- Diagnostic testing, which participants found expensive, could be freely available to students with communication and socialization challenges.
- Volunteering helps participants build life skills (e.g., communicating interpersonally, managing schedules) and diminish mischaracterizations (Cappelli et al., 2020). Fittingly, institutions can partner with early intervention and special needs services in their communities and recruit students with and without autism to participate.
- Practitioners serving autistic students could decrease overstimulation by creating sensory spaces (Essary et al., 2020; Park et al., 2020) in academic and residential buildings. These spaces are quiet, include

sensory tools (e.g., blankets, fidgets), reduce anxiety, and ease information-processing.

Methodological Implications

This study's findings offer guidance for researchers working with diverse communities. For example, interviewers should reword questions to make them more explicit for participants, including people with and without disabilities. Second, eliciting recommendations from participants for transforming their institutions is challenging. Therefore, scholars should consider combining verbal and visual data so participants can share their critiques most comfortably. Enacting these inclusive data collection practices can enrich findings.

Limitations of Dissertation

Findings are limited for several reasons. First, to avoid data collection and analysis delays, I only included those participants who could ethically consent for themselves. Thus, I did not have participants with legal guardians or representatives responsible for making financial, legal, or medical decisions (e.g., conservatorship, power of attorney). This decision decreased my sample from 17 to 16 participants. Second, participants are all Caucasian, so the sample had limited racial diversity. Finally, three participants neither participated in follow-up interviews nor submitted everyday life maps due to their health challenges. Although I encountered limitations in sampling, the findings are rich, and their rigor is reflected in my data analysis (Chapter Four).

Recommendations for Future Research

From the findings, there are multiple avenues for qualitative and quantitative research. First, future research should involve autistic students with legal guardians or representatives. Second, including more racially diverse participants would help researchers explore the ways intersecting identities affect everyday information practices. Third, scholars may examine the implementation of UDL in higher education institutions. Finally, applying my proposed model in different information contexts (e.g., libraries, medical facilities, schools) could help test the ideas of sensory and social well-being.

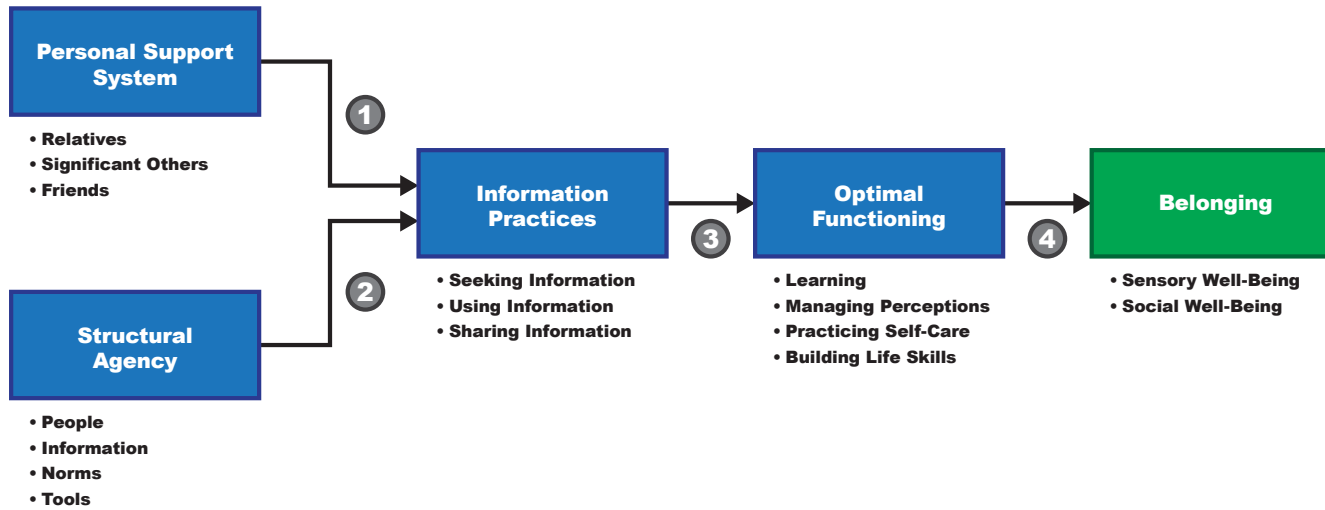


Figure 14. Proposed Theoretical Model of Sensory and Social Well-Being

Conclusion

This study examined the ways in which an institution's people, information, norms, and tools influence autistic students' everyday information practices. Institutions are positioned to help satisfy autistic students' information needs by enhancing their sensory and social well-being. Specifically, (a) designing accessible instruction, (b) reducing mischaracterizations, and (c) enhancing functioning are seldom explored ways higher education institutions can universally support students with and without autism. Transforming higher education shall require practitioners across institutions to shift everyday responsibilities from students' personal support systems to themselves.

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APPENDICES

Appendix A: Institutional Review Board Outcome Letters



November 04, 2021

Kevin Joseph Mallary,
UTK - College of Communication and Inf - Information Sciences

Re: UTK IRB-21-06655-XP
Study Title: Investigating Autistic Students' Information Practices for Mastering Everyday Academic Life
Through the Lens of Structural Agency: A Grounded Theory Study

Dear Kevin Joseph Mallary:

The UTK Institutional Review Board (IRB) reviewed your application for the above referenced project. It determined that your application is eligible for expedited review under 45 CFR 46.110(b)(1) Categories (6) and (7). The IRB has reviewed these materials and determined that they do comply with proper consideration for the rights and welfare of human subjects and the regulatory requirements for the protection of human subjects.

Therefore, this letter constitutes full approval by the IRB of your application version 1.1 as submitted. You are approved to enroll a maximum of 30 participants. Approval of this study will be valid from November 04, 2021 to 11/03/2022.

Approval Information:

- Expedited cat. 6 and 7
- N= 30
- Waiver of documentation of consent
- CR Required (PI Student)
- Application v. 1.1

Approved Documents:

- Consent for research participation nov 2 2021 v. 1.1
- Recruitment email message nov 2 v. 1.1
- Interview guide October 8 2021 v. 1.0

Institutional Review Board | Office of Research & Engagement
1534 White Avenue Knoxville, TN 37996-1529
865-974-7697 865-974-7400 fax irb.utk.edu

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- Demographics questionnaire October 8 2021 v. 1.0
- Everyday life map October 5 2021 v. 1.0

Any revisions in the approved application, consent forms, instruments, recruitment materials, etc., must also be submitted to and approved by the IRB prior to implementation. In addition, you are responsible for reporting any unanticipated serious adverse events or other problems involving risks to subjects or others in the manner required by the local IRB policy.

Finally, re-approval of your project is required by the IRB in accord with the conditions specified above. You may not continue the research study beyond the time or other limits specified unless you obtain prior written approval of the IRB.

Sincerely,



Lora Beebe, Ph.D., PMHNP-BC, FAAN
Chair

Institutional Review Board | Office of Research & Engagement
1534 White Avenue Knoxville, TN 37996-1529
865-974-7697 865-974-7400 fax irb.utk.edu

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November 24, 2021

Kevin Joseph Mallary,
UTK - College of Communication and Inf - Information Sciences

Re: UTK IRB-21-06655-XP

Study Title: Investigating Autistic Students' Information Practices for Mastering Everyday Academic Life Through the Lens of Structural Agency: A Grounded Theory Study

Dear Kevin Joseph Mallary:

The UTK Institutional Review Board (IRB) reviewed your application for **revision** of your previously approved project, referenced above.

The IRB determined that your application is eligible for **expedited** review under 45 CFR 46.110(b)(2). The following revisions were approved as complying with proper consideration of the rights and welfare of human subjects and the regulatory requirements for the protection of human subjects:

- Revised questions in interview guide and the order of questions

Stamped Document:

- Interview guide October 8 2021 v. 1.1

Approval does not alter the expiration date of this project, which is 11/03/2022.

Any additional revisions in the approved application, consent forms, instruments, recruitment materials, etc., must be submitted to and approved by the IRB prior to implementation. In addition, you are responsible for reporting any unanticipated serious adverse events or other problems involving risks to subjects or others in the manner required by the local IRB policy.

Finally, **re-approval** of your project is required by the IRB in accord with the conditions specified above. You may not continue the research study beyond the time or other limits specified unless you obtain prior written

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approval of the IRB.

Sincerely,



Lora Beebe, Ph.D., PMHNP-BC, FAAN
Chair

Institutional Review Board | Office of Research & Engagement
1534 White Avenue Knoxville, TN 37996-1529
865-974-7697 865-974-7400 fax irb.utk.edu

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March 09, 2022

Kevin Joseph Mallary,
UTK - College of Communication and Inf - Information Sciences

Re: UTK IRB-21-06655-XP

Study Title: Investigating Autistic Students' Information Practices for Mastering Everyday Academic Life Through the Lens of Structural Agency: A Grounded Theory Study

Dear Kevin Joseph Mallary:

The UTK Institutional Review Board (IRB) reviewed your application for **revision** of your previously approved project, referenced above.

The IRB determined that your application is eligible for **expedited** review under 45 CFR 46.110(b)(2). The following revisions were approved as complying with proper consideration of the rights and welfare of human subjects and the regulatory requirements for the protection of human subjects:

Added data collection at Univ. of Kentucky
Updated questionnaire for Univ. of S. Carolina and Univ. of Kentucky
Application v. 1.3
Informed consent March 2 2022 v. 1.0
Interview guide March 2 2022 v. 1.0
Demographics questionnaire March 2 2022 v. 1.0

Approval does not alter the expiration date of this project, which is 11/03/2022.

Any additional revisions in the approved application, consent forms, instruments, recruitment materials, etc., must be submitted to and approved by the IRB prior to implementation. In addition, you are responsible for reporting any unanticipated serious adverse events or other problems involving risks to subjects or others in the manner required by the local IRB policy.

Finally, re-approval of your project is required by the IRB in accord with the conditions specified above. You may not continue the research study beyond the time or other limits specified unless you obtain prior written approval of the IRB.

Sincerely,

Lora Beebe, Ph.D., PMHNP-BC, FAAN
Chair

Institutional Review Board | Office of Research & Engagement
1534 White Avenue Knoxville, TN 37996-1529
865-974-7697 865-974-7400 fax irb@utk.edu

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Appendix B: Recruitment Email Message

Recruitment Email Message

Dear [Mr. Ndiaye or Dr. Wilhoit or Dr. Burgin],

I am writing to ask for your assistance with recruiting participants for my dissertation, which examines the information practices of autistic students, a vastly understudied population.

Having received Institutional Review Board approval, I seek to interview undergraduate and graduate autistic students at The University of Tennessee at Knoxville, during which I will ask them about their experiences balancing the academic, personal, and social demands of higher education. ~~Each initial and follow-up interview shall last 30–45 minutes, and all participants will receive a \$50.00 UTK VolShop gift card for their time.~~ Each initial and follow-up interview shall last 30–45 minutes, and all participants will receive a \$25.00 UTK VolShop gift card after each interview.

Please forward the following email message to currently enrolled autistic students. Your support of my dissertation would be greatly appreciated. Thank you.

Best,

Kevin

Suggested Subject: Receive \$50 UTK VolShop Gift Card for Participating in Autism Dissertation Research

Dear Students,

You are being invited to participate in a dissertation research study about autism in higher education.

Kevin Mallary, a Ph.D. Candidate in the College of Communication & Information, who is finishing his degree, is interviewing UTK autistic students about their experiences balancing higher education's academic, personal, and social demands. Findings may be used to improve higher education for autistic students.

You are being asked to participate in two interviews. ~~Each interview shall last 30–45 minutes, and every participant will receive a \$50.00 UTK VolShop gift card at the end of the second session.~~ Each interview shall last 30–45 minutes, and every participant will receive a \$25.00 UTK VolShop gift card at the end of each session. If you are

IRB NUMBER: UTK IRB-21-06655-XP
IRB APPROVAL DATE: 11/04/2021

interested in participating, please visit

https://utk.co1.qualtrics.com/jfe/form/SV_8eaduszuW9tgyQ, or email the researcher:

kmallary@vols.utk.edu.

Thank you for your consideration of this opportunity.

[Signature]

IRB NUMBER: UTK IRB-21-06655-XP
IRB APPROVAL DATE: 11/04/2021

Appendix C: Consent Forms

Consent for Research Participation

Research Study Title: Investigating Autistic Students' Information Practices for
Mastering Everyday Academic Life

Researchers: Kevin Mallary, Ph.D. Candidate,
The University of Tennessee at Knoxville
Devendra Potnis, Ph.D., Faculty Adviser,
The University of Tennessee at Knoxville

Why am I being asked to be in this research study?

You are being asked to participate in this research study because you have been identified as a student on the autism spectrum.

What is this research study about?

The purpose of the research study is to explore the information practices of autistic students, a vastly understudied population.

How long will I be in the research study?

Your total participation in this study will last between 60–90 minutes, depending on the length of your interview sessions.

What will happen if I say, “Yes, I want to be in this research study”?

If you agree to be in this study, you will be asked to participate in two in-person or virtual interviews for 30–45 minutes each. During both interviews, the researchers will ask you questions about how your autism diagnosis affects your completion of coursework. You will also be asked to create a drawing between your two interviews. However, you should not worry about the quality of your picture since nobody will be able to identify it as yours.

Are there accommodations provided during this study?

Should you need any accommodations to participate in this research, you can request them in the next form. If you request specialized services (e.g., captioning, interpreting),

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the researchers will coordinate with Student Disability Services to confidentially ensure your comfort.

What happens if I say, “No, I do not want to be in this research study”?

Being in this research study is up to you. At any time, you are welcome to leave the study, no questions asked.

What happens if I say “Yes” but change my mind later?

Even if you decide to be in the study now, you can change your mind and stop at any time. If you choose to stop before the study is completed, please contact the researchers. If you decide to stop after the study is conducted, your data may have already been used, so please contact the researchers as soon as possible.

Are there any possible risks to me?

As is the case with any research, there are always risks to participating. Because your voice will be recorded during both interview sessions, it is possible that someone could hear the recordings and figure out that you participated in this study. However, to minimize this potential risk, the audio recordings will be safely stored throughout the research and then destroyed at the end.

Another risk may come from the interview questions themselves. Some questions might make you feel uncomfortable. To prevent any discomfort, you are free to answer any questions you like and decline any questions you do not wish to reply to.

Are there any benefits to being in this research study?

The researchers do not expect you to benefit from being in this study. However, your participation may help the researchers learn more about how autistic students search for and use it to complete their coursework. In addition, the researchers hope the knowledge gained from this study will benefit others in the future.

Who can see or use the information collected for this research study?

The researchers will protect your confidentiality by taking the following precautions:

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- Using an identifier instead of your name on any documents and materials in this study, including the calendar used to schedule your interviews, the drawing created between your interviews, the UTK VolShop gift card you receive, and the file names of your interviews the audio recordings of your discussions.
- Storing the audio recordings of your interviews on a password-protected computer belonging to the researchers. After this study, your recordings will be destroyed.
- If information from this study is published or presented at scientific meetings, your name and other personal information will not be used.

The researchers will make every effort to prevent anyone from knowing that you provided information or what information came from you. However, although it is unlikely, there are times when others may need to see the information that the researchers collect about you. These include:

- People at The University of Tennessee at Knoxville, who oversee research to make sure it is conducted properly.
- Government agencies (such as the Office for Human Research Protections in the U.S. Department of Health and Human Services) and others responsible for watching over the research's safety, effectiveness, and conduct.
- If a law or court requires us to share the information, we must follow that law or final court ruling.

What will happen to my information after this study is over?

The researchers will keep your information to use for future research. However, your name and other personally identifiable information will be deleted from your research data collected as part of the study.

Will I be paid for being in this research study?

Yes. ~~You will electronically receive a \$50.00 UTK VolShop gift card at the end of your second interview.~~ You will electronically receive a \$25.00 UTK VolShop gift card at the end of each interview.

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Will it cost me anything to be in this research study?

If your interview sessions with the researchers are in-person rather than on Zoom, you are expected to provide your transportation to and from the interview location.

Who can answer my questions about this research study?

If you have questions or concerns about this study or have experienced a research-related problem or injury, contact the researchers, Kevin Mallery (kmallery@vols.utk.edu) or 336-655-3286) or Devendra Potnis (dpotnis@utk.edu) or 865-974-8612). For questions or concerns about your rights or to speak with someone other than the researchers about the study, contact:

Institutional Review Board

The University of Tennessee at Knoxville
1534 White Avenue
Blount Hall, Room 408
Knoxville, TN 37996-1529
Phone: 865-974-7697
Email: utkirb@utk.edu

Screening Items

[To verify that the participant (a) is on the autism spectrum, (b) does not have a cognitive impairment which limits their ability to ethically consent, and (c) does not have a legal guardian or representative responsible for making legal decisions, I include the following screening items]

- Are you on the autism spectrum?
 - Yes
 - No
- Based on what you have read, select each of the following statements that are true:
 - I can leave this study anytime without penalty [True]
 - There is zero risk to participating in this research [False]
 - The researchers will do their best to protect my privacy [True]

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- My information will be kept for future research [True]
 - I will receive a \$1,000.00 gift card to the UTK VolShop [False]
- Do you have a legal guardian or representative who is responsible for making legal decisions on your behalf?
 - Yes
 - No

Statement of Consent

I have read this form, and the research study has been explained to me. I agree to be audio recorded during each interview. I have been able to ask questions of the researchers. If I have further questions or concerns, I have been told who to contact. By selecting "I Agree," I agree to be in this study.

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Consent for Research Participation

Research Study Title: Investigating Autistic Students' Information Practices for
Mastering Everyday Academic Life

Researchers: Kevin Mallery, Ph.D. Candidate,
The University of Tennessee at Knoxville
Devendra Potnis, Ph.D., Faculty Adviser,
The University of Tennessee at Knoxville

Why am I being asked to be in this research study?

You are being asked to participate in this research study because you have been identified as a student on the autism spectrum.

What is this research study about?

The purpose of the research study is to explore the information practices of autistic students, a vastly understudied population.

How long will I be in the research study?

Your total participation in this study will last between 60–90 minutes, depending on the length of your interview sessions.

What will happen if I say, “Yes, I want to be in this research study”?

If you agree to be in this study, you will be asked to participate in two in-person or virtual interviews for 30–45 minutes each. During both interviews, the researchers will ask you questions about how your autism diagnosis affects your completion of coursework. You will also be asked to create a drawing between your two interviews. However, you should not worry about the quality of your picture since nobody will be able to identify it as yours.

Are there accommodations provided during this study?

Should you need any accommodations to participate in this research, you can request them in the next form. If you request specialized services (e.g., captioning, interpreting),

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the researchers will coordinate with **Disability Resource Center** to confidentially ensure your comfort.

What happens if I say, “No, I do not want to be in this research study”?

Being in this research study is up to you. At any time, you are welcome to leave the study, no questions asked.

What happens if I say “Yes” but change my mind later?

Even if you decide to be in the study now, you can change your mind and stop at any time. If you choose to stop before the study is completed, please contact the researchers. If you decide to stop after the study is conducted, your data may have already been used, so please contact the researchers as soon as possible.

Are there any possible risks to me?

As is the case with any research, there are always risks to participating. Because your voice will be recorded during both interview sessions, it is possible that someone could hear the recordings and figure out that you participated in this study. However, to minimize this potential risk, the audio recordings will be safely stored throughout the research and then destroyed at the end.

Another risk may come from the interview questions themselves. Some questions might make you feel uncomfortable. To prevent any discomfort, you are free to answer any questions you like and decline any questions you do not wish to reply to.

Are there any benefits to being in this research study?

The researchers do not expect you to benefit from being in this study. However, your participation may help the researchers learn more about how autistic students search for and use it to complete their coursework. In addition, the researchers hope the knowledge gained from this study will benefit others in the future.

Who can see or use the information collected for this research study?

The researchers will protect your confidentiality by taking the following precautions:

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- Using an identifier instead of your name on any documents and materials in this study, including the calendar used to schedule your interviews, the drawing created between your interviews, the **Kentucky gift card** you receive, and the file names of your interviews the audio recordings of your discussions.
- Storing the audio recordings of your interviews on a password-protected computer belonging to the researchers. After this study, your recordings will be destroyed.
- If information from this study is published or presented at scientific meetings, your name and other personal information will not be used.

The researchers will make every effort to prevent anyone from knowing that you provided information or what information came from you. However, although it is unlikely, there are times when others may need to see the information that the researchers collect about you. These include:

- People at The University of Tennessee at Knoxville, who oversee research to make sure it is conducted properly.
- Government agencies (such as the Office for Human Research Protections in the U.S. Department of Health and Human Services) and others responsible for watching over the research's safety, effectiveness, and conduct.
- If a law or court requires us to share the information, we must follow that law or final court ruling.

What will happen to my information after this study is over?

The researchers will keep your information to use for future research. However, your name and other personally identifiable information will be deleted from your research data collected as part of the study.

Will I be paid for being in this research study?

Yes. You will electronically receive a \$25.00 **Kentucky gift card** at the end of each interview.

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Will it cost me anything to be in this research study?

If your interview sessions with the researchers are in-person rather than on Zoom, you are expected to provide your transportation to and from the interview location.

Who can answer my questions about this research study?

If you have questions or concerns about this study or have experienced a research-related problem or injury, contact the researchers, Kevin Mallery (kmallery@vols.utk.edu) or 336-655-3286) or Devendra Potnis (dpotnis@utk.edu) or 865-974-8612). For questions or concerns about your rights or to speak with someone other than the researchers about the study, contact:

Institutional Review Board

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1534 White Avenue
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Knoxville, TN 37996-1529
Phone: 865-974-7697
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Screening Items

[To verify that the participant (a) is on the autism spectrum, (b) does not have a cognitive impairment which limits their ability to ethically consent, and (c) does not have a legal guardian or representative responsible for making legal decisions, I include the following screening items]

- Are you on the autism spectrum?
 - Yes
 - No
- Based on what you have read, select each of the following statements that are true:
 - I can leave this study anytime without penalty [True]
 - There is zero risk to participating in this research [False]
 - The researchers will do their best to protect my privacy [True]

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- My information will be kept for future research [True]
 - I will receive a \$1,000.00 Kentucky gift card [False]
- Do you have a legal guardian or representative who is responsible for making legal decisions on your behalf?
 - Yes
 - No

Statement of Consent

I have read this form, and the research study has been explained to me. I agree to be audio recorded during each interview. I have been able to ask questions of the researchers. If I have further questions or concerns, I have been told who to contact. By selecting "I Agree," I agree to be in this study.

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Appendix D: Demographics Questionnaires

Demographics Questionnaire

- What is your name? [Open-ended text]
- What is your preferred email address? [Open-ended text]
- How did you learn about this study?
 - Student Disability Services
 - Postsecondary Autism Support Services
 - Future Program
 - Peer (e.g., classmate, roommate)
 - Relative
 - Other: [Open-ended text]
- What is your age? [Open-ended text]
- What is your gender?
 - Female
 - Male
 - Non-binary
 - Prefer not to say
- What is your current year in school?
 - Freshman
 - Sophomore
 - Junior
 - Senior
 - Graduate Student
- What is your academic major or program of study? [Open-ended text]
- Are you registered to receive accommodations through Student Disability Services?
 - Yes
 - No
- If so, please specify the accommodations that you have received: [Open-ended text]
- Have you received any accommodations in the past academic year?

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- Yes
 - No
- Which, if any, of the following assistive technologies do you use? Select all that apply:
 - Adaptive devices (e.g., keyboards, joysticks)
 - Audiobooks and e-books
 - Captioning and transcription services
 - Reading and writing fluency software (e.g., Dragon Naturally Speaking, Kurzweil)
 - Screen-readers (e.g., JAWS, ZoomText)
 - Smart Pens (e.g., Livescribe)
 - Virtual reality experiences
 - Other: [Open-ended text]
 - None
- Please list any accommodations you need to participate in the interviews. If you do not need any accommodations to participate in the discussions, you may leave this field blank. [Open-ended text]
- What day(s) each week are you most available for an interview? Select all that apply:
 - Monday
 - Tuesday
 - Wednesday
 - Thursday
 - Friday
 - Saturday
 - Sunday
- On the day(s) you selected, what time(s) are you most available for an interview? Select all that apply:
 - 9:00 AM – Noon
 - Noon – 3:00 PM
 - 3:00 – 6:00 PM

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- Where would you like to have your interview?
 - On-campus in a private office
 - Online in a private Zoom meeting

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Demographics Questionnaire

- What is your name? [Open-ended text]
- What is your preferred email address? [Open-ended text]
- How did you learn about this study?
 - Disability Resource Center
 - Peer (e.g., classmate, roommate)
 - Relative
 - Other: [Open-ended text]
- What is your age? [Open-ended text]
- What is your gender?
 - Female
 - Male
 - Non-binary
 - Prefer not to say
- What is your current year in school?
 - Freshman
 - Sophomore
 - Junior
 - Senior
 - Graduate Student
- What is your academic major or program of study? [Open-ended text]
- Are you registered to receive accommodations through the Disability Resource Center?
 - Yes
 - No
- If so, please specify the accommodations that you have received: [Open-ended text]
- Have you received any accommodations in the past academic year?
 - Yes
 - No

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- Which, if any, of the following assistive technologies do you use? Select all that apply:
 - Adaptive devices (e.g., keyboards, joysticks)
 - Audiobooks and e-books
 - Captioning and transcription services
 - Reading and writing fluency software (e.g., Dragon Naturally Speaking, Kurzweil)
 - Screen-readers (e.g., JAWS, ZoomText)
 - Smart Pens (e.g., Livescribe)
 - Virtual reality experiences
 - Other: [Open-ended text]
 - None
- Please list any accommodations you need to participate in the interviews. If you do not need any accommodations to participate in the discussions, you may leave this field blank. [Open-ended text]
- What day(s) each week are you most available for an interview? Select all that apply:
 - Monday
 - Tuesday
 - Wednesday
 - Thursday
 - Friday
 - Saturday
 - Sunday
- On the day(s) you selected, what time(s) are you most available for an interview? Select all that apply:
 - 9:00 AM – Noon
 - Noon – 3:00 PM
 - 3:00 – 6:00 PM
- Where would you like to have your interview?
 - On-campus in a private office

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- Online in a private Zoom meeting
- Over the phone

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Appendix E: Semi-Structured Interview Guides

Semi-Structured Interview Guide

- [Start audio recording]
- Thank you so much for taking the time to participate in this interview. Today's conversation, which should last between 30 and 45 minutes, will be about your experiences as someone on the autism spectrum in higher education. Specifically, I will ask you questions about balancing the academic and everyday demands of higher education. If at any point during our time together you feel uncomfortable with any of the questions that I ask, or you do not wish to continue, let me know. Also, you are free to take a break at any point. Your participation is entirely voluntary. Do you have any questions before we begin?
- [Items to be addressed in the initial interview]
 - I would like to start our interview by asking you about your academic experiences. For this group of questions, think about a challenging course you took this past year.
 - Which course was it?
 - What about this course was challenging? What specific challenges did you encounter? How did being on the autism spectrum influence these challenges?
 - What types of assignments (e.g., essays, presentations, quizzes) were you required to complete during the course?
 - What were your professor's expectations of students? How did the professor's expectations influence how you completed your assignments?
 - What other expectations shaped your experience completing assignments (e.g., institutional, social, personal)? How did they influence your work?
 - What documents or materials (e.g., articles, books, notes, podcasts, videos) did you use when completing your assignments? Where would you find these documents or materials (e.g., academic library,

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e-books, Google Scholar)? Were they helpful? Why or why not? How would you decide which information was useful?

- What technologies (e.g., computer, Canvas, mobile device, assistive technology) would you use when completing your assignments? Were they helpful? Why or why not?
 - Where would you complete your assignments (e.g., classroom, academic library, dormitory)? Why did you choose these places?
 - Who would you consult as you completed your assignments (e.g., professors, peers, academic librarians, relatives)? What information or resources did (a) professors, (b) peers, (c) staff members, or (d) relatives offer? Were they helpful? Why or why not? What information or resources did you share with them? How did you communicate (e.g., in-person, email, social media)?
 - Which accommodations or services (e.g., Student Disability Services, academic library services, tutoring services) provided by the University did you use when completing your assignments? Were they helpful? Why or why not?
 - At any point during the course, did you lack the information or resources you needed to complete your assignments? If so, what did you do? Please describe your experience.
- Next, I would like to discuss your everyday experiences as a student. Being a student involves making everyday decisions. Examples of everyday decisions include identifying a career, becoming friends with someone, receiving medical care, or finding a place to live. Aside from those examples, there are many decisions students make.
- What is an everyday decision you have made this past year?
 - What challenges did you encounter in your decision-making? How did being on the autism spectrum influence your decision-making?
 - What expectations affected your decision-making (e.g., institutional, social, personal)? How did they influence your decision-making?

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- What documents or materials (e.g., blog articles, books, notes, podcasts, videos) did you use when making your decision? Where would you find these documents or materials (e.g., blogs, Google, social media, YouTube)? Were they helpful? Why or why not? How would you decide which information was useful?
 - What technologies (e.g., computer, mobile device, assistive technology) would you use to make your decision? Were they helpful? Why or why not?
 - What places were essential to your decision-making (e.g., academic library, community organization, dormitory, Student Health Services)? Why did you choose these places?
 - Who would you consult as you made your decision (e.g., professors, peers, academic librarians, relatives)? What types of information or resources did these people give you? Were they helpful? Why or why not? What information or resources did you share with them? How did you communicate (e.g., in-person, email, social media)?
 - Which accommodations or services (e.g., Student Disability Services, academic library services, counseling services) provided by the University did you use when making your decision? Were they helpful? Why or why not?
 - At any point, did you feel like you did not have the information or resources you needed to make your decision? If so, what did you do? Please describe your experience.
- To help me better understand your experience as a student on the spectrum at UTK, before our final interview, please draw on this paper an illustration of your everyday responsibilities. Consider including the types of information you need, along with the behaviors, challenges, technologies, people, and places involved in your daily life. You may draw pictures, flow charts, or mind maps, or simply write text. Whatever you decide, do not worry about your artistic ability. To submit your drawing, follow the steps listed (Appendix F).

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- Before we finish our interview, is there anything we did not discuss that you wish to share?
- Thank you for taking the time to participate in this interview. I look forward to our final discussion.
- [Items to be addressed in the follow-up interview]
 - I want to discuss the drawing you completed after our last interview.
 - Would you walk me through the process of creating your drawing?
 - [Follow-up questions about the information needs, behaviors, challenges, technologies, people, and places depicted in the participant's drawing]
 - Finally, I have some questions about your overall experience as a student, including balancing your academic and everyday demands.
 - What are the most important questions or concerns (e.g., academics, socialization) you have had as a student?
 - How did you go about finding answers to your questions? What information or resources did you need to answer them? Where would you find what you needed? How did people (e.g., professors, peers, academic librarians, relatives) help you, if at all?
 - How did the University help you find the answers you needed?
 - What did you learn from answering your questions?
 - Before we conclude our final interview, is there anything we did not discuss that you wish to share?
 - Thank you for taking the time to participate in this study. I look forward to sharing my findings with you, and with your help, improving access to higher education for all students who are on the spectrum.
 - [Electronically deliver UTK VolShop gift card to the participant]
- [Stop audio recording]

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Semi-Structured Interview Guide

- [Start audio recording]
- Thank you so much for taking the time to participate in this interview. Today's conversation, which should last between 30 and 45 minutes, will be about your experiences as someone on the autism spectrum in higher education. Specifically, I will ask you questions about balancing the academic and everyday demands of higher education. If at any point during our time together you feel uncomfortable with any of the questions that I ask, or you do not wish to continue, let me know. Also, you are free to take a break at any point. Your participation is entirely voluntary. Do you have any questions before we begin?
- [Items to be addressed in the initial interview]
 - I would like to start our interview by asking you about your academic experiences. For this group of questions, think about a challenging course you took this past year.
 - Which course was it?
 - What about this course was challenging? What specific challenges did you encounter? How did being on the autism spectrum influence these challenges?
 - What types of assignments (e.g., essays, presentations, quizzes) were you required to complete during the course?
 - What were your professor's expectations of students? How did the professor's expectations influence how you completed your assignments?
 - What other expectations shaped your experience completing assignments (e.g., institutional, social, personal)? How did they influence your work?
 - What documents or materials (e.g., articles, books, notes, podcasts, videos) did you use when completing your assignments? Where would you find these documents or materials (e.g., academic library,

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e-books, Google Scholar)? Were they helpful? Why or why not? How would you decide which information was useful?

- What technologies (e.g., computer, Canvas, mobile device, assistive technology) would you use when completing your assignments? Were they helpful? Why or why not?
 - Where would you complete your assignments (e.g., classroom, academic library, dormitory)? Why did you choose these places?
 - Who would you consult as you completed your assignments (e.g., professors, peers, academic librarians, relatives)? What information or resources did (a) professors, (b) peers, (c) staff members, or (d) relatives offer? Were they helpful? Why or why not? What information or resources did you share with them? How did you communicate (e.g., in-person, email, social media)?
 - Which accommodations or services (e.g., [Disability Resource Center](#), academic library services, tutoring services) provided by the University did you use when completing your assignments? Were they helpful? Why or why not?
 - At any point during the course, did you lack the information or resources you needed to complete your assignments? If so, what did you do? Please describe your experience.
- Next, I would like to discuss your everyday experiences as a student. Being a student involves making everyday decisions. Examples of everyday decisions include identifying a career, becoming friends with someone, receiving medical care, or finding a place to live. Aside from those examples, there are many decisions students make.
- What is an everyday decision you have made this past year?
 - What challenges did you encounter in your decision-making? How did being on the autism spectrum influence your decision-making?
 - What expectations affected your decision-making (e.g., institutional, social, personal)? How did they influence your decision-making?

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- What documents or materials (e.g., blog articles, books, notes, podcasts, videos) did you use when making your decision? Where would you find these documents or materials (e.g., blogs, Google, social media, YouTube)? Were they helpful? Why or why not? How would you decide which information was useful?
 - What technologies (e.g., computer, mobile device, assistive technology) would you use to make your decision? Were they helpful? Why or why not?
 - What places were essential to your decision-making (e.g., academic library, community organization, dormitory, Student Health Services)? Why did you choose these places?
 - Who would you consult as you made your decision (e.g., professors, peers, academic librarians, relatives)? What types of information or resources did these people give you? Were they helpful? Why or why not? What information or resources did you share with them? How did you communicate (e.g., in-person, email, social media)?
 - Which accommodations or services (e.g., Disability Resource Center, academic library services, counseling services) provided by the University did you use when making your decision? Were they helpful? Why or why not?
 - At any point, did you feel like you did not have the information or resources you needed to make your decision? If so, what did you do? Please describe your experience.
- To help me better understand your experience as a student on the spectrum at The University of Kentucky, before our final interview, please draw on this paper an illustration of your everyday responsibilities. Consider including the types of information you need, along with the behaviors, challenges, technologies, people, and places involved in your daily life. You may draw pictures, flow charts, or mind maps, or simply write text. Whatever you decide, do not worry about your artistic ability. To submit your drawing, follow the steps listed (Appendix F).

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- Before we finish our interview, is there anything we did not discuss that you wish to share?
- Thank you for taking the time to participate in this interview. I look forward to our final discussion.
- [Items to be addressed in the follow-up interview]
 - I want to discuss the drawing you completed after our last interview.
 - Would you walk me through the process of creating your drawing?
 - [Follow-up questions about the information needs, behaviors, challenges, technologies, people, and places depicted in the participant's drawing]
 - Finally, I have some questions about your overall experience as a student, including balancing your academic and everyday demands.
 - What are the most important questions or concerns (e.g., academics, socialization) you have had as a student here?
 - How did you go about finding answers to your questions? What information or resources did you need to answer them? Where would you find what you needed? How did people (e.g., professors, peers, academic librarians, relatives) help you, if at all?
 - How did the University help you find the answers you needed?
 - What did you learn from answering your questions?
 - Before we conclude our final interview, is there anything we did not discuss that you wish to share?
 - Thank you for taking the time to participate in this study. I look forward to sharing my findings with you, and with your help, improving access to higher education for all students who are on the spectrum.
- [Stop audio recording]
- [Electronically deliver Kentucky gift card to the participant]

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Appendix F: Everyday Life Map Template

My Drawing

Participant ID _____

In this space, please draw an illustration of how you have balanced the academic and everyday demands of being a student over the past year . Consider including any of the following items:

- Challenging assignments
- Major everyday decisions
- Information or resources needed
- Documents or materials used
- Technologies used
- University accommodations used
- Objects used
- People involved
- Places visited
- Problems faced

Do not worry about your artistic ability. Your drawing will be anonymous.

Following the steps below, please upload a photo of this entire paper before your final interview:

1. Visit the online submission form by using your phone's camera to scan the QR code on the right
2. Enter your Participant ID, which is at the top and bottom right of this paper
3. Upload your photo using the online form



Participant ID _____

Appendix G: Codebook for Data Analysis and Member-Checking

1. Participants' Concerns			
General Concerns (Axial Codes)	Specific Concerns (Initial Codes)	Description (Properties of Codes)	Examples (Excerpts from Interviews)
Ableism	Inaccessible Instruction	Professors often provide vague instructions for completing assignments, do not clarify deadlines, and seldom communicate with their students.	"I have assignments from some classes that are vague, and I personally need solid instructions that tell me what I need to do, how I need to do it, and what it's going to look like when it's done. And I tend to struggle with those assignments a lot because I don't have an outline. I don't know what to do. I don't know where to go. So, I end up just overthinking it a lot, and that really trips me up because I end up doing something completely different than what the professor wanted or what was intended."
	Mischaracterizing Autism	People's erroneous attitudes toward autism can affect students with autism.	"Not enough people talk about [autism] and it's still considered, I don't want to say taboo, but many people still don't understand it. It's frustrating because I have seen how other people treat neurodivergent kids. I want to help other people see it's not what they think because there's a stigma to it."
	Unreceptive to Accommodations	Professors are unreceptive to autistic students' accommodations, and they are sometimes unreceptive to accommodations which modify	"I've had a comment from my public speaking professor. She was like, 'If you have trouble with the time constraints, then maybe you just need

General Concerns (Axial Codes)	Specific Concerns (Initial Codes)	Description (Properties of Codes)	Examples (Excerpts from Interviews)
		assignments, particularly adjustments that allow for additional time.	to take a different public speaking class because the time constraints can't accommodate you.' And it's just been frustrating because the people making those decisions are neurotypical, and they don't have a deep enough understanding of everyday life because there are some things where I just can't help it, and that's why I need accommodations.”
Overstimulation	Crowding	Crowding is another form of overstimulation which hinders information-processing.	“When I'm studying, I can't go to the library or anywhere that's super public to work, because trying to focus on my work while there's other things going on, people walking past me, things like that, makes it extremely difficult.”
	Physical Sensitivity	Sensitivity to sounds, textures, and odors comprise physical sensitivity.	“One of the lessons [in a psychology class] was on sound, noise, and how the brain interprets that. I had issues doing that specific lesson because, to demonstrate, the teacher had loud noises that I was not okay with. Since getting my diagnosis, I can now leave the classroom if that happens again, which I'm very relieved to hear.”
Psychosocial Barriers	Anxiety	Adjusting to higher education generates anxiety for participants.	“I had an exam, so I scheduled it with [Student Disability Services]. Then, I had a panic attack, and I missed it. So,

General Concerns (Axial Codes)	Specific Concerns (Initial Codes)	Description (Properties of Codes)	Examples (Excerpts from Interviews)
			I tried to reschedule it, and they said, 'Oh, we can't do that.' They asked me to come in and take the exam. They emailed me at 10:00 in the morning and asked me to come in at 2:00 to take the exam. I did not appreciate that . . . For people with anxiety, at least for myself, there can be a lot of anxiety around tests. So, I need two days or so to mentally prepare myself. Not just to academically prepare, but to be ready for that environment."
	Emotional Blindness	Emotional blindness involves difficulty when interpreting satirical writings or symbolism.	"I had an assignment, and I completely missed the satire element to it. But it was difficult because I looked up the assignment online and asked other people, and nobody mentioned the satire element to me. So, I completely missed it because it's just not something that comes to mind."
	Limited Social Awareness	Limited social awareness involves difficulty behaving appropriately in conversations, forming friendships, and recovering from social missteps.	"Figuring out how to make friends is harder. I feel like that's a problem everybody has, but I think it's harder for autistic people. I happened to get put in a project group the first semester of freshman year. And I live with that person now, so that worked out well. It took a long time for me to be comfortable around them, though,

General Concerns (Axial Codes)	Specific Concerns (Initial Codes)	Description (Properties of Codes)	Examples (Excerpts from Interviews)
			because [it was a] new place, new person, new friendship, relationship. It was fine the more time I spent with that person and our other friends."

2. Participants' Responses to Concerns

General Responses (Axial Codes)	Specific Responses (Initial Codes)	Description (Properties of Codes)	Examples (Excerpts from Interviews)
Learning	Consulting Professors	Students seek clarification from their professors if reading materials or consuming lectures is confusing.	"[Some professors] take time outside of their office hours to explain things. I can email them and ask questions, and they'll try to explain it in ways I can understand . . . [We] could go to [one professor's] office hours two or three times a week, for several hours a day online, so that helped. If we asked a question, she would turn on her whiteboard screen. Then she would work the problem out, so we understood it."
	Receiving Tutoring	Students learn by receiving tutoring.	"The [Teaching Assistants] are helpful. Because if we had a question about any of the fish, they would always have an answer or they would go find out the answer and come back to tell us. They had some study tricks and uploaded lecture videos as extra materials."
	Using Study Aids	To learn, students with autism use study aids, including tablet devices, supplementary videos, mobile applications, and sensory tools (e.g., noise-cancelling headphones, fidget objects).	"I have earbuds and backup headphones; they're noise canceling. So, if I go somewhere that's a little noisy to get work done, I can put those in, and it helps me tune out some of the sensory information, mainly the audio stuff. And I can have nothing on

General Responses (Axial Codes)	Specific Responses (Initial Codes)	Description (Properties of Codes)	Examples (Excerpts from Interviews)
			and no noise, I can play white noise – like the ocean crashing, rain – or I can play music, and it helps me. So, that's only five senses and eliminates one of them."
	Working With Peers Versus Working Independently	Peers working together build knowledge and hold each other accountable. Since social interactions heighten anxiety, some students prefer working on assignments alone.	"It's helpful because we're able to pass information back and forth, like, 'Hey, what did he say in class today? I didn't understand.' And this person can clarify. Or 'I don't understand this part of the assignment. Can someone explain it to me?' And they can send a quick message to let me know. We'll even share Quizlets through GroupMe."
Building Life Skills	"Panic Researching" for Living Independently	Living independently can heighten participants' anxiety, and in select cases, cause panic attacks.	"I have an anxiety disorder. I feel that more information is better. So, when I get panicked about something, I will learn all the information I can about it. Or if something in the news worries me, I need to learn everything I can. I call it 'panic researching' because I am panicking. But I'm also getting so much information and learning from it, so it's useful."
	Becoming Financially Literate	Becoming financially literate (e.g., budgeting, obtaining credit) is an important life skill.	"For a long time, I was winging it. Recently I've been making my budget page in Notion, so every month, I have

General Responses (Axial Codes)	Specific Responses (Initial Codes)	Description (Properties of Codes)	Examples (Excerpts from Interviews)
			a way to track everything I spent and where it went. And it makes me accountable because it shows me if I'm negative or positive for that month. And it makes me feel not guilty . . . One of my biggest issues is hyper-focusing on my special interests a lot. And they tend to be like video games or comic books, which are very easy to spend money on."
	Researching Careers	Students browse websites to research careers and identify internships.	"I use the Internet to read about careers that I wanted. Maybe I might look at a YouTube video, like a day in the life of a person with this career."
Managing Perceptions	Managing Others' Perceptions	To manage others' perceptions of themselves, students either conceal or disclose their autism.	"Sometimes, [disclosing] can be helpful, and sometimes it can throw people off. You must, in my experience, gauge if you're good enough friends with somebody, and it's how you tell them, but that can help people understand why you get anxious about certain things, and why you're asking, 'Hey, was it weird when I did this?'"
	Managing Self-Perceptions	Participants also manage their perceptions of themselves by (a) refusing or underutilizing disability support services (e.g.,	"Without my friends, I don't really have a safe space where I can unmask and be visually autistic and not be worried, because a lot of my other friends are

General Responses (Axial Codes)	Specific Responses (Initial Codes)	Description (Properties of Codes)	Examples (Excerpts from Interviews)
		accommodations, assistive technologies), (b) finding their place (e.g., friendships, participating in on-campus organizations), and (c) embracing their autism (i.e., accepting their diagnoses).	also autistic. Nobody's going to look at me weird if I touch a weird texture and shake my hands. Or nobody's going to look at me weird because I'm not looking at them."
Practicing Self-Care	Achieving Balance	Students achieve balance by managing their time spent studying and socializing with their peers.	"For me, there is balance, and I'm getting closer to balance. But, even when I have friends, accommodations, and resources, it still feels like [school, work, and masking] can weigh me down, especially during finals."
	Accepting Support	Accepting support (e.g., advice, physical assistance) from their personal and institutional support systems is important for students practicing self-care. Peers, significant others, and relatives comprise personal support systems. Aside from personal support systems, institutional supports (e.g., disability support services, counseling) can help them care for themselves.	"Usually, I have somebody that can ask. If I want someone to give me genuine advice, I go to my best friend. If something is more about my future, I go to my parents. And then something that's happening in my personal life, that's probably because of my autism, I go to my counselor."
	Finding Solace	Studying in quiet places, retreating to sensory spaces, and depending on service animals are ways of finding solace.	"[Studying in a public place] might help me concentrate more, but I just like working with no one around. You don't have to focus on being appropriate or anything. For example, if I was in a

General Responses (Axial Codes)	Specific Responses (Initial Codes)	Description (Properties of Codes)	Examples (Excerpts from Interviews)
			library, I probably wouldn't be listening to music super loudly, but I can do that in my residence hall because nobody's there."

3. Participants' Recommendations for Institutions

General Recommendations (Axial Codes)	Specific Recommendations (Initial Codes)	Description (Properties of Codes)	Examples (Excerpts from Interviews)
Design Accessible Instruction	Make Information Accessible	Recorded lectures and captioning are instructional practices for making information accessible.	"Recorded lectures across the board would be beneficial. Many professors post their slides and speaker notes, but if I miss class because I have a panic attack, looking at slides and reading speaker notes doesn't have the same effect as if I was in that class. The closest way to replicate that would be to have a video of that lecture."
	Promote Hands-On Learning	Gaining field experience would better prepare students for employment than completing traditional assessments (e.g., examinations, papers).	"Honestly, I hate sitting down and taking a test. That is not a good way to show how much you have gained from the class. If you get a question wrong, you could still know how to answer the question. It's just that question might have been a bit hard, or maybe you misread the question. When teachers are grading, they're like, 'Oh, this person doesn't know this because they got the question wrong.' It would be more inclusive to sit down and do something more creative than answer some questions on a piece of paper."
	Provide Explicit Instructions and "Spoon-Feed"	Professors should provide students with explicit, step-by-step instructions for assignments.	"My parents always call this spoon-feeding, but I'd like professors to give more reminders about deadlines"

General Recommendations (Axial Codes)	Specific Recommendations (Initial Codes)	Description (Properties of Codes)	Examples (Excerpts from Interviews)
			because I will simply forget. Usually, professors just say it once, it's on the syllabus, and that's all there is to it. Nothing until it's due. And that doesn't work for me as somebody with autism."
Reduce Mischaracterizations	Form Community Partnerships	Institutions partner with community organizations (e.g., early intervention services) that serve people with autism.	"I think [the university] should talk more to the Knoxville community and kids with autism. Early intervention is the most important thing, and if we do that, I think there could be someone else like me out there. I don't know if there's anyone else out there like me. I'm sure hoping there is. I'm sure there is, but they're pretty much hidden, like me."
	Inspire Autism Allies	Raising awareness of autism and reducing others' mischaracterizations is important.	"Just because it's invisible doesn't mean it's not there . . . So, the [Disability Resource Center] is doing a campaign, they did this last semester, on invisible disabilities. My group, the Neurodiverse Educational Social Initiative, did this. They gave out these t-shirts. I haven't worn mine yet, but it says, 'Now you see me' . . . When people wear the shirts, it shows that you can have a disability and you won't look disabled. But just because you can't see it, doesn't mean it's not there."

General Recommendations (Axial Codes)	Specific Recommendations (Initial Codes)	Description (Properties of Codes)	Examples (Excerpts from Interviews)
	Promote Accessible Events	Promoting accessible events helps members of the autism community practice socializing. Gatherings of students with disabilities, particularly those with psychosocial barriers (e.g., anxiety, limited social awareness), would help reduce mischaracterizations.	"I struggle with socializing, so it was great to find a group that I fit in with. I think that is invaluable, because sure, I could sit in my room alone all day and only do schoolwork, but I'd go crazy. And so, making it easier for people with disabilities to get involved, to find their people, would be excellent. I think that'd be a perfect way to help people."
Enhance Students' Functioning	Improve Disability Support Services	Disability support services should publicize the tools they provide (e.g., academic accommodations, assistive technologies) to students with autism. Also, simplifying the process for receiving accommodations is recommended. Further, disability support services can improve by making diagnostic testing free to students who report academic and social challenges.	"One thing that I think the university could do to better support students on the spectrum is to have a separate office within Student Disability Services, that is more specialized for students on the spectrum . . . People working there would have more experience dealing with people on the spectrum than with people with general disabilities . . . One way to make it more relatable would be to have employees who are on the spectrum."
	Create Sensory Spaces	Sensory spaces reduce overstimulation by providing students with silence and sensory tools (e.g., blankets, fidget objects).	"Maybe a quiet, isolated place would be nice. Because that's where I feel I excel. It could be a small room in an academic building, or the library, or a big room that's been split into rooms."

General Recommendations (Axial Codes)	Specific Recommendations (Initial Codes)	Description (Properties of Codes)	Examples (Excerpts from Interviews)
	Provide Life Skills Training	Institutions can provide life skills training, such as financial literacy training, for students with and without autism.	"I would love to see some sort of one-credit-hour financial literacy class, something to teach you about getting a credit card, and when you should get a credit card . . . That would be very beneficial, especially for people who are disabled and living on their own now. That's very much missing."

VITA

Originally from Orlando, Florida, Kevin J. Mallery attended Wake Forest University in Winston-Salem, North Carolina, where he earned bachelor's and master's degrees in communication. After earning his master's degree, Kevin taught in the Department of Communication at Western Carolina University in Cullowhee, North Carolina, while earning a Doctor of Philosophy in Communication & Information from The University of Tennessee at Knoxville. Since Kevin is profoundly deaf from being born four months early, he seeks to advance accessibility and inclusion in education through his scholarship, teaching, and service. Starting in July 2022, Kevin will be an Assistant Professor of Library & Information Studies at Old Dominion University in Norfolk, Virginia. Kevin is grateful for the mentorship and encouragement he received throughout his career.