

Challenges and Strengths of College Students with Autism Spectrum Disorder and Attention-Deficit/Hyperactivity Disorder

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## ABSTRACT

Emerging adults who have Autism Spectrum Disorder (ASD) often encounter difficulties within the university setting. Despite an increase in the number of students with ASD enrolled in postsecondary educational institutions, there are few reports on the social, academic, and/or other needs of college students with ASD. The purpose of this study was to assess the perspectives of parents of emerging adults with ASD and ADHD, in order to inform efforts to address the poor postsecondary outcomes of students with ASD. Survey data were collected from parents who had a son or daughter in one of three educational placement groups (parents of high school students, parents of postsecondary students, and parents of individuals aged 18-25 not enrolled in education) among two disorders; ASD and ADHD. Participants were recruited nationally to participate in an online survey. Parents of emerging adults with ASD identified social interactions and daily living as primary difficulties for their son or daughter with ASD. Significant differences emerged with respect to difficulties among emerging adults with ADHD, who identified difficulties related to executive functioning and attention. Social interaction training was an identified needed service by parents of emerging adults with ASD. Additionally, independent living training was a common core service requested by parents of individuals with ASD and parents of individuals with ADHD. Results suggest that the postsecondary profile of parent-reported difficulties and needed services remains distinct for the diagnostic groups ASD and ADHD. These difficulties should be considered within the context of intervention for postsecondary students with ASD and ADHD.

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# Challenges and Strengths of College Students with Autism Spectrum Disorder and Attention-Deficit/Hyperactivity Disorder

## **Introduction**

Emerging adulthood is a developmental period typically spanning the ages of 18 to 25 years, characterized by the primary goal of identity-formation via a series of transitions toward increasing independence (Arnett, 2000), as well as challenges related to increasing independence and responsibility. This transitional period allows for training, developmental maturation, and postsecondary education which, in turn, produces adults with the ability to contribute to societal obligations (Arnett, 2007). The identity formation that occurs during this period influences relationship development, motivation to complete an academic degree or vocational training, and choosing an academic major or field of work (Shattuck et al., 2014). As critical as this developmental period is, it has been grossly understudied in populations which may require additional support in some capacity.

A sizable number of individuals with a disability classification enroll in some form of postsecondary education. ‘Disability classification’ refers to a student belonging to one of the thirteen categories established by the Individuals with Disabilities Education Act (IDEA; i.e., autism, deaf-blindness, deafness, emotional disturbance, hearing impairment, intellectual disability, multiple disabilities, orthopedic impairment, other health impairment, specific learning disability, speech or language impairment, traumatic brain injury, or visual impairment). Approximately 46% of emerging adults with disabilities and 63% of emerging adults without a disability classification transition to a postsecondary environment (Newman et al., 2011). Emerging adults are faced with increased demands upon entering the postsecondary domain (Wenzel & Brown, 2014). These demands are often amplified for students with neurodevelopmental disorders. Neurodevelopmental disorders are impairing conditions with

symptom onset early in development. Additionally, deficits are developmental in nature and have clinical impairment in the personal, social, academic or occupational domains.

Neurodevelopmental disorders such as ASD and ADHD frequently co-occur (American Psychiatric Association, 2013). In addition to age-normative demands faced by all young adults matriculating into college, students with neurodevelopmental disabilities, along with other disability classifications, must also learn how to self-advocate to obtain services or accommodations during this transition.

Many students with a disability classification are heavily supported during their high school years through an Individualized Education Plan (IEP) or Section 504 (504 Plan). An IEP provides needed services such as academic accommodations, speech therapy, counseling, social skill groups, specialized academic instruction, etc. Section 504 of the Rehabilitation Act of 1973 states that the needs of students with disabilities be met at a level equitable to the needs of a student without a disability. Specifically, students who acquire a 504 Plan are supported in the general education setting. A 504 plan is for students who have a disability, but do not qualify for special education services under The Individuals with Disabilities Improvement Act (IDEIA, 2004)

IDEIA governs special education services through the high school years and ceases to encompass individuals in their postsecondary placement. IDEIA mandates that transition planning for students entitled to special education services through an IEP should begin between 14-16 years of age (Public Law 108-446, 2004). Having high school students engage in transition planning has been regarded as a feature of positive postsecondary outcomes in a variety of disability classifications (Roberts, 2010). Despite structured transition plans crafted during the high school years, structured support systems are often not readily available and/or

not utilized at the college level. This is often compounded by a loss of additional services provided outside the school, such as psychotherapy (Levy & Perry, 2011; Shattuck, et al., 2012). Once students with disabilities graduate from secondary school, their services and accommodations under IDEIA cease. Adults with disabilities, including students with special needs in the postsecondary setting, are protected by the Americans with Disabilities Act (ADA), a system reliant on self-advocacy and demonstration of need. Specifically, students are expected to undertake the process of seeking academic or other services independently, rather than their parents doing this for them because the students (usually) are legally considered to be adults. Specifically, in order to receive special academic accommodations, students must approach appropriate school personnel with documentation detailing their disability. This process can be intimidating and lengthy. Once accommodations are granted, academic services are typically limited to appropriate accommodations which do not alter the core curriculum (Wenzel & Brown, 2014). Many of the services implemented during the K-12 IEP are no longer covered in the ADA, which governs the college environment (Wenzel & Brown, 2014).

Individuals in the United States are granted legal stature at the age of 18 when they are considered “adults”. Consequently, educational support staff in the university setting are legally required to communicate with the adult client, oftentimes deliberately forgoing communication with current or past support networks such as parents due to legal mandates and ethical guidelines. As such, these emerging adults with a disability are placed in a new role- one that requires self-advocacy and self-determination; oftentimes, they feel unprepared for this role, as it involves responsibilities for which they’ve often not had exposure to or training in. As a result, services are often not utilized to their full potential. Parents struggle with supporting their grown children with a disability and encouraging/fostering independence while at college. Although

parents may have the most intimate knowledge of their own grown child's needs and strengths, they are often powerless to help – due to legal protections related to the privacy of their adult children and the need to foster independence in their offspring.

Despite documented difficulties among postsecondary students with disabilities, little investigation has been initiated to determine the needs, challenges, and strengths from the parents' perspective. The current investigation sought to inform our understanding of the needs of a subset of emerging adults in the postsecondary arena from a parent stakeholder perspective. Specifically, the parent perspective of emerging adults with Autism Spectrum Disorder (ASD) was the primary focus of the study. By integrating a comparator group, parents of emerging adults with Attention-Deficit/Hyperactivity Disorder (ADHD), the parent-reported needs of emerging adults with ASD can be examined relative to those with ADHD, allowing for exploration of what concerns might be specific to ASD.

### **ASD & ADHD: Needed Student Populations**

Emerging adults with ASD and ADHD were chosen as the focus of this study primarily due to overlapping characteristics in a variety of functional domains. Both neurodevelopmental disorders co-occur at high rates in Western countries (American Psychiatric Association, 2013; Levy et al., 2010; Mattila et al., 2010). Additionally, in the postsecondary setting, emerging adults with ASD and ADHD both experience poor academic, vocational, and social outcomes in adolescence and beyond (Cadman et al., 2012). Executive functioning deficits widely apparent in both disorders are hypothesized as one common facet contributing to poor educational outcomes (Fleming & McMahon, 2012; Gobbo & Shmulsky, 2013; Hewitt, 2011). Despite vast impairment, few free services beyond academic accommodations exist for individuals with ASD

or ADHD in the postsecondary arena. As a result, it has been hypothesized that parents aid their child in the postsecondary environment to ensure success (Cadman et al., 2012).

### **Autism Spectrum Disorder**

ASD is a neurodevelopmental disorder which is characterized by difficulties in social interaction, deficits in social communication, and stereotyped repetitive behavior and interests (American Psychiatric Association, 2013). The prevalence of ASD has been steadily rising since its initial identification as a quantifiable disorder in the 1940s. It is estimated that approximately 1 in every 68 children has ASD (US Centers for Disease Control and Prevention, 2014). As such, the number of adolescents and adults who have been identified with ASD (especially without cognitive impairment) is steadily increasing (VanBergeijk, Klin, & Volkmar, 2008). Moreover, the majority of children diagnosed with ASD continue to exhibit social impairment through adolescence and into adulthood (VanBergeijk et al., 2008). Although the core symptomatology of ASD is present throughout the lifespan, research focused on ASD in adolescence and adulthood has been under-developed. Transition from the high school to college setting appears to be a period where individuals with ASD experience unique challenges and needs (Adreon & Durocher, 2007). Programs are springing up across the country to help facilitate transition to postsecondary institutions for students on the spectrum, yet there has been little to no systematic research on the specific types of support needs and developmental challenges faced by this growing student population. This research attempts to address this gap.

**ASD and postsecondary enrollment.** The number of postsecondary students with ASD continues to grow in the United States (White, Ollendick, & Bray, 2011). However, it is difficult to ascertain the rate of enrollment of individuals with ASD because several students do not

reveal their diagnoses to educational support staff (Wenzel & Brown, 2014). Despite an expanding number of individuals with ASD being involved in higher education, little research has been conducted on their transition to postsecondary institutions, successful completion of postsecondary studies, and educational and vocational outcomes. Cognitively unimpaired (often referred to as “high functioning” in the literature) individuals with ASD are often capable of the academic rigor associated with university attendance. Success has been documented, especially in individuals who utilize appropriate supports in the postsecondary setting (Hudson, 2013; VanBergeijk et al., 2008).

When comparing postsecondary outcomes of young adults with ASD to those with other disabilities, individuals with ASD have the third lowest university enrollment among all disability categories recognized by IDEIA (Wei, Yu, Shattuck, Mccracken, & Blackorby, 2013). A 2013 investigation found that students with hearing impairment, vision impairment, orthopedic impairment, speech and language impairment, other health impairment, learning disability, traumatic brain injury, and emotional disturbance have higher 2-year and 4-year postsecondary enrollment than students with ASD (Wei, Yu, et al., 2013). The enrollment rate of students with ASD, at around 32%, was higher than that for students with identified multiple disabilities and intellectual disability. Despite low overall postsecondary enrollment rates, students with ASD have relatively high postsecondary enrollment in science, technology, engineering, and mathematics (STEM) majors when compared to other disability categories (Wei, Yu, et al., 2013; Wei, Christiano, et al., 2013). Of those who are enrolled in the postsecondary strata, basic translational challenges exist that impede overall success.

The majority of individuals with diagnosed ASD do not seek admittance to postsecondary institutions, do not get accepted to college, and have higher drop-out rates than neurotypical

students (Glennon, 2001; Hurlbutt & Chalmers, 2004; Wei, Yu, et al., 2013). Specifically, approximately 32% of students with ASD apply for admittance and attend postsecondary institutions (Wei, Christiano, et al., 2013). Rates of college attendance decrease further when individuals with ASD have more severe impairments, comorbid psychiatric problems, and lack of access to appropriate educational services (Taylor & Seltzer, 2011). Low enrollment rates are seen despite interest in postsecondary educational opportunities among individuals with ASD and their parents (Camarena & Sarigiani, 2009). Parental expectations, annual household income, academic success, and the school's primary post-high school goal have all been identified as predictors of participation in postsecondary schooling for individuals with ASD (Chiang, Cheung, Hickson, Xiang, & Tsai, 2012).

**Difficulties in the postsecondary environment.** The first two years after high school completion are characterized by low rates of paid employment or continuation of schooling (Shattuck et al., 2012). Anecdotally, it appears that young adults with ASD experience marked difficulties during the transitional period after high school. Although often well-equipped academically, students with ASD tend to experience scholastic underachievement in the postsecondary environment (Kapp, Gantman, & Laugeson, 2011). Additionally, increased stress and biological changes in emerging adults with ASD have been hypothesized to influence overall success (Pinder-Amaker, 2014). When compared to other disability categories, individuals with ASD were more likely than individuals with an intellectual disability or individuals with a speech and language impairment to be disengaged from postsecondary education (Shattuck et al., 2012). Several hypotheses regarding challenges for students with ASD in the postsecondary setting exist. Some researchers assert that initial difficulties during the transition period after high school are compounded by specific ASD features (e.g., difficulty with changes in

longstanding routines or environments; Test, Smith, & Carter, 2014). The transition to a postsecondary environment is a change in a student's daily routine in the high school setting. Also notable are the known impairments in communication, social skills, skills of daily living, and executive functioning that likely pose unique challenges for a student with ASD integrating into a university setting (Hewitt, 2011; VanBergeijk, Klin, & Volkmar, 2008).

Impaired communication and self-determination negatively impact later outcomes for students and emerging adults with recognized disabilities. Students with disabilities have improved outcomes after formal schooling if they implement self-determination (Chambers et al., 2007; Field & Hoffman, 1994; Solberg, Howard, Gresham & Carter, 2012; Wehmeyer & Palmer, 2003). Self-determination is a developmental construct which is present across the lifespan. Specifically, self-determination encompasses the skills, attitudes, and actions that enable individuals to be empowered autonomously (Shogren & Turnbull, 2006; Wehmeyer, 2001). This has several implications for successful transition to the postsecondary environment. Namely, communicating strengths, interests, future goals, and advocating for supports and resources all are communication-based skills of self-determination which have been hypothesized as difficult for students with ASD (Lee & Carter, 2012).

Social deficits are inherent to the diagnostic presentation of ASD (American Psychiatric Association, 2013). These social atypicalities have implications throughout the lifespan, with distinct characteristics of the postsecondary setting ultimately contributing to diminished overall success. Specifically, nonverbal social cues are inherent to the postsecondary learning environment. For example, school personnel reported that students with ASD struggle with detecting when and how to contribute to group-based academic activities, social norms such as determining appropriate times to turn off their computers in class, and missed social rules such as

talking too long in class or cutting other students off before they have finished (Gobbo & Shmulsky, 2013). In addition to academic implications, social inclusion remains limited in adulthood (Howlin, Moss, Savage, & Rutter, 2013). Core symptoms of ASD may plateau or regress after adolescence (Smith, Maenner & Seltzer, 2012) making the emerging adult period of development a crucial time for evidence-based intervention.

Executive functioning is loosely defined as the ability to engage in goal-directed behavior (Barkley, 1997; Roberts & Pennington, 1996). Executive functioning entails selecting and maintaining an action which drives performance on a task. Inhibition, planning, shifting, flexibility, organization, working memory, and self-monitoring all work together to comprise the construct of executive functioning (Barkley, 1997; Barkley, 2000). Difficulties in executive functioning skills are seen in a number of clinical disorders, such as ASD (Liss et al., 2001; Pennington & Ozonoff, 1996). Shifts in academic tasks and schedules have been shown as difficult for postsecondary students with ASD (Gobbo & Shmulsky, 2013; Pennington & Ozonoff, 1996). For example, students with ASD may fall behind on a number of activities necessary for academic success such as shifts in scheduled due dates or changes to the syllabus, moving from one activity to the next in class, or in planning homework appropriately (Gobbo & Shmulsky, 2013). Executive functioning deficits are hypothesized to create extra difficulties across a host of disorders; most notably, ADHD.

### **Attention-Deficit/Hyperactivity Disorder**

Attention-Deficit/Hyperactivity Disorder (ADHD) is a neurodevelopmental disorder characterized by symptoms of inattention and/or hyperactivity and impulsivity. This symptomatology must be present before the age of 12 and pervasively impair the social,

vocational/academic, and/or home environments (American Psychiatric Association, 2013). Although once considered a disorder of childhood, ADHD remains an impairing diagnostic classification for approximately 2.5% of adults (American Psychiatric Association, 2013). Approximately 15 to 65% of individuals diagnosed with ADHD in childhood maintain clinical diagnostic criteria into adulthood (Faraone, Biederman, & Mick, 2006).

**ADHD and postsecondary enrollment.** Clinically interfering ADHD is highly prevalent among postsecondary students, with estimates between 2-8% (Dupaul, Weyandt, O'Dell, & Varejao, 2009; McKee, 2008; Norvilitis, Ingersoll, Zhang & Jia, 2008). Among students who utilize university-based accommodations, approximately 25% receive accommodations based on an ADHD diagnosis (Wolf, 2001). Individuals with ADHD have poor academic outcomes in the postsecondary setting. Specifically, students with ADHD have lower grade point averages (GPAs) and take longer to complete their academic degrees compared to students without ADHD (Barkley et al., 2008; Schwanz, Palm, & Brallier, 2007). Further, individuals diagnosed with ADHD as children have lower graduation rates than students without ADHD (Barkley et al., 2008). Similar to students with ASD, emerging adults with ADHD enrolled in a postsecondary placement display lower levels of social skills and quality of life (Shaw-Zirt, Popali-Lehane, Chaplin, & Bergman, 2005). Additionally, postsecondary students exhibit increased risk for patterns of substance abuse (Rooney, Chronis-Tuscano, & Yoon, 2012). Overall, students with ADHD appear to struggle in the postsecondary arena (Fleming & McMahon, 2012).

A pilot study that qualitatively explored the identified needs of students with ADHD identified three primary themes which help or hinder tasks in the postsecondary setting: 1) gaining insight about ADHD, 2) managing life and 3) utilizing sources of support (Meaux,

Green, & Broussard, 2009). However, the parental perspective has not been examined in relation to postsecondary students with ADHD.

### **The Role of Parents in Transition to Postsecondary Education**

Parents play a pivotal role in assisting their offspring with the identity development, emotional and educational/vocational transitions associated with the emerging adulthood period. Specifically, parents of 18-25 year olds reported that they did not see their son/daughter as attaining “adult” status and, consequently, interacted with/parented their child accordingly (Arnett, 2000, 2007).

The parental burden (i.e., emotional status) for caregivers of emerging adults with ASD and ADHD is high (Cadman et al., 2012). Caregiving for an emerging adult with ASD equated similar levels of burden for those caring for a son/daughter with a traumatic brain injury. Likewise, it has been found that caregivers of individuals with ADHD face a similar degree of burden to those who care for individuals with dementia (Cadman et al., 2012). When accounting for severity levels of related symptomatology, individuals with more severe symptoms of ADHD show significantly more caregiver burden. Cai and Richdale (2015) report significant parental support with organizational tasks in the postsecondary domain. Heavy parental burden and involvement necessitate caregiver-informed studies which can be used to inform the development of appropriate treatments.

For the present study, parents were chosen as the primary informant group because they are an integral component of educational planning for their children at the primary through high school grade levels. Further, parents of individuals with ASD identify a need and desire to be involved in transitions to adulthood (Stoner, Angell, House, & Bock, 2007). Consideration of

their thoughts regarding perceived strengths and difficulties at the college level was a natural extension due to the intimate perspective that caregivers possess. Additionally, individuals with high functioning ASD over-rate their personal social functioning when compared to parent-report (Lerner, Calhoun, Mikami, & De Los Reyes, 2012). This suggests that some individuals with ASD may make inaccurate judgments about their social abilities. Utilizing a parent informant group may be a better measure of social needs for individuals with ASD in the university domain. Additionally, parent involvement in the transition from secondary to postsecondary education is regarded as one factor involved in favorable later outcomes in the educational setting (Eckes & Ochoa, 2005).

### **Preliminary Studies**

Parents have been identified as critical in helping their children with ASD secure educational placements at the postsecondary level (Smith & Anderson, 2013). The literature illustrating poor postsecondary outcomes for individuals with ASD necessitates a needs-analysis of students with ASD who are college-bound or of college-age to inform successful transition planning and educational support reforms at the college level. To our knowledge, there have been only two preliminary studies examining the needs and challenges of college students with ASD from a parent perspective (Duke, Conner, Kreiser, Hudson, & White, 2013; Morrison, Sansosti, & Hadley, 2009).

Duke and colleagues (2013) utilized a focus group with college-enrolled students with ASD, and an online survey of 5 parents of enrolled college students with ASD and two other informant groups ( $n=3$  students with ASD and  $n=12$  educational support staff). The results of the study yielded themes indicating difficulty in managing life tasks, poor time management skills,

and decreased direction toward self-directed goals. Morrison and colleagues (2009) assessed four parents of high school students with ASD. The results of the study identified perceived challenges with self-advocacy and a parent desire for appropriate supports and accommodations at the university level.

The present study sought to expand this preliminary work by targeting a larger participant group from diverse geographical and socioeconomic strata. Additionally, the present study looked at three informant groups (parents of high school students with ASD, parents of college students with ASD, and parents of college-aged students with ASD) to assess if perceived needs vary as a function of group identification. Additionally, parents of individuals with ADHD were used as a comparison group, to determine if these identified needs are unique to ASD, or rather, similar across a comparable disability group.

### **Specific Aims**

In order to determine the transition and in-college support needs of emerging adults with ASD, this study surveyed parents of adolescents and emerging adults with either ASD or ADHD to ascertain their perceptions of need. The overall goal of the proposed study was to evaluate the challenges and needs encountered by students with ASD in higher-level academic institutions.

**Primary Aims:** We sought to isolate the parent-identified challenges and supports needed of students with ASD who are either attending a postsecondary institution or are postsecondary-bound. Group differences among the challenges and supports between the six parent informant groups were examined. **Secondary Aims:** Parent perceived strengths of students with ASD were ascertained, in addition to parental reported reasons for why some individuals who are postsecondary-capable do not attend an educational institution.

Due to the exploratory nature of the present study and the limited prior research in this area, a priori hypotheses were limited. To inform structured transition services for college students and college-bound adolescents with ASD, research must elucidate the challenges which are impeding academic, social, and independent living success. Based on preliminary data with a small sample size (Duke et al., 2013), it was hypothesized that parents of students with ASD would report difficulty in the university context with time-management, self-determination, social isolation, and self-regulation. We expected group differences with regards to parents of individuals with ASD and ADHD. Specifically, we hypothesized that parents of individuals with ADHD would not identify difficulties with social isolation, self-determination, and self-regulation. However, similar endorsement rates of challenges with time management were expected. Additionally, we hypothesized that parents of postsecondary students with ASD would express a greater need than parents of students with ADHD for 1) weekly supportive therapy, 2) independent training living, 3) daily or weekly check-ins with support staff, and 4) planned opportunities to interact socially with other students with their shared disability in an unstructured setting.

## **Method**

### **Procedure**

This project was approved by the Virginia Tech Institutional Review Board for human subject research (See Appendix A). In order to reach a broad and diverse participant group without geographical constraints, the present study used an online survey. The survey was created in SurveyGizmo ([www.surveygizmo.com](http://www.surveygizmo.com)), a secure data-collection aid. Data collection occurred over a 10-month period.

After receiving the online survey link, participants consented to study participation as the first step in the online process, per Virginia Tech IRB protocol. By answering a series of demographic questions, individuals then either proceeded to the online survey or were informed that they had not met eligibility criteria for the study. Inclusion criteria for participants consisted of self-report of parental status to a son or daughter between the ages of 16-25 with either ASD or ADHD, dependent on the referent survey.

The ASD survey took an average of 34 minutes (*range: 6-170 minutes*) and the ADHD survey took an average of 34 minutes (*range: 5-122 minutes*) to complete. To ensure anonymity, participant e-mail addresses were not linked to participant data. Participant e-mail addresses were only used as a means of distributing honoraria to participants. Participants were not allowed to advance to the next set of questions until all of the quantitative items were completed. On completed surveys, there were no missing items on any quantitative questions.

## **Participants**

Participants were men and women from two broad informant groups: parents of individuals with ASD and parents of individuals with ADHD. Within these two groups, parents were further subdivided, based on the age and educational status of their son/daughter with ASD/ADHD: 1) high school students between the ages of 16-25, 2) college students between the ages of 16-25, and 3) individuals aged 16-25 who do not have co-occurring intellectual disability and are not currently enrolled in high school or college.

Parents were defined as self-identified current or former legal guardians. The first informant group (parents of high school students with ASD without cognitive impairment who are between the ages of 16-25) was targeted to address the parental perceived needs of students

who are college bound. Age 16 was chosen as the lower bound of the age range because that is the maximum age at which transition planning, within the IEP, should have begun. A comparison informant group (parents of high school students with ADHD who are between the ages of 16-25) was also established. Parents of individuals with ASD were not excluded if their child also had a diagnosis of ADHD.

The other informant groups (parents of individuals between the ages of 18-25 who are either enrolled in college or not) were aimed to capture parents of individuals with ASD and ADHD who are in the emerging adulthood developmental period. The criterion of having a child between the ages of 18 and 25 is due to prior research that suggests that ages 18-25 encompass emerging adulthood, a period of change exemplified by exploration of one's own identity (Arnett, 2000). Patterns which are created during this developmental period are likely to persist into adulthood (Arnett, 2000). By assessing parents of emerging adults (regardless of postsecondary enrollment status), we were able to consider perspectives of parents whose grown children may have dropped out of college, determined that the university was not the right fit, or encountered insufficient services in the university setting. Informant group identification was not able to be verified, which was an inherent limitation of the research study approach. Rather, inclusion criteria (i.e., belonging to one of the three parental groups and having a child with ASD) was derived from participant self-report.

Recruitment for the online survey component of the study targeted parents of adolescents and young adults with ASD and ADHD via flyers and online resources. Local advertising occurred in Southwest Virginia (namely in the community, 4-year and 2-year college campuses, and local counseling offices) and disseminated through web-based research portals. University disability offices, online listservs, participant databases of the Virginia Tech Department of

Psychology, and Virginia Tech ASD registries (e.g., Virginia Tech Center for Research and Treatment, Virginia Tech Autism Center, VT Daily News, VT Graduate Student Listserv) were targeted in the New River Valley region of Virginia.

At the national level, ASD and ADHD-specific online blogs and websites were specifically targeted for participant recruitment. Specifically, online advertisements were posted on autism, ADHD, and parent teenage/young adult related forums, blogs, discussion lists (e.g. Organization for Autism Research, Autism Speaks, Children and Adults with Attention Deficit Hyperactivity Disorder [CHADD], Parent resource centers, College Autism Spectrum, Berkeley Parents Network), and social networking sites (e.g. Facebook and Meetup). Online advertisements were sent out to postsecondary institutions in all 50 states. Additionally, individual counselors and psychological services centers were contacted in all 50 states.

In an effort to enroll a sufficient number of students and obtain a representative sample, modest honoraria were offered to parents as incentive for participation. All participants received an honorarium at the completion of the survey in the form of an electronic Amazon gift card. Parents of an individual with ASD received a \$10 Amazon gift card between October 16, 2014 and December 1, 2014, at which time the funding source changed. Between December 1, 2014 and August 29, 2015 parent participants of an individual with ASD or ADHD received a \$5 Amazon gift card.

One hundred and forty three people began the survey. A subsample size of 99 was used for all quantitative analyses. The following reasons resulted in cases being excluded: only partially completed the survey ( $n = 27$ ), son/daughter who did not meet inclusion criteria (i.e., no ASD or ADHD diagnosis, outside of the 16-25 year age range,  $n = 14$ ), resided outside of the

United States as determined by their IP address ( $n = 3$ ). See Table 1 for a visual of included participants.

A power analysis was conducted using G-Power 3.1 software (Faul, Erdfelder, Buchner, & Lang, 2009) for a two-tailed ANOVA, using a large effect size of 0.80 and an *alpha* of 0.05 divided among 3 subgroups (0.0167). The power analysis indicated that a total sample size of  $n = 210$  (i.e., 35 participants in each of the 6 informant groups), would achieve sufficient power (0.80) in order to detect a large effect and be able to compare the three groups statistically for the analysis. A second power analysis was conducted for a two-tailed ANOVA to determine sufficient power in order to detect a comparison among just the two diagnostic groups ( $ES = 0.80$ ,  $\alpha = 0.05$ ). The power analysis indicated that a total sample size of  $n = 52$  (i.e., 26 participants in each of the 2 diagnostic groups) would achieve sufficient power (0.80) in order to detect a large effect and be able to compare the two diagnostic groups statistically for the analysis. The survey remained open for 10.5 months and during this time we secured 99 total participants with slightly uneven distribution among the subgroups. It was determined that, due to recruitment constraints, obtaining a fully-powered sample among all subgroups was not feasible within our timeline.

## **Evaluation Measures**

**Demographics.** A brief demographic questionnaire was administered to all participants during the online session. Information regarding the parent participant's age, level of education obtained, ethnicity, and socioeconomic status was collected from parents. Parents were also asked to provide demographic information about their child. Specifically, the age of their child, if they are currently enrolled in a postsecondary institution, the type of college attended, and psychiatric diagnoses. For participants completing the demographic information online, the

information obtained informed eligibility. If inclusion criteria were met, individuals were able to continue on to the online survey.

### **Primary Measure.**

*Online Survey.* Prior to online data collection, individual interviews were conducted to inform content development of the final online survey. Four participants participated in either a remote telephone ( $n = 3$ ) or in-person ( $n = 1$ ) interview. Interview participants were local to the Southeastern United States. All participants were mothers of emerging adults with ASD. Participants engaged in an unstructured interview regarding the needs, challenges, and strengths of their son or daughter. The interviews were audio recorded. Interviews spanned an average of 42.59 minutes. The age of offspring with ASD ranged from 18-24 ( $M = 21.5$ ). Two individuals were enrolled in a 2-year postsecondary institution, 1 was enrolled in a 4-year university, and 1 individual was not currently enrolled in a postsecondary institution, although he had attempted postsecondary schooling in the past. Primary themes of the unstructured interviews were support for social skills, executive functioning, self-concept, skills of daily living, independence, anxiety and other comorbidities. These themes were used as the basis for the creation of the final online survey.

The online survey contained content designed specifically for this study (See Appendix B). After discerning the most prevalent themes from the parent interviews, an alpha version of the survey was developed. The survey underwent a multi-stage refinement process. First, the survey was reviewed internally by faculty and students in the departments of Psychology, Special Education, and Educational Research and Development. Next, the survey was distributed to three expert consultants in the field of ASD, external to the primary institution.

Input derived from reviewers was integrated into the final survey for distribution. Finally, the survey was internally piloted before distribution to the general public.

Forced choice integrated with free response modalities was used to increase richness of the dataset and identification of themes across the respondent groups. Qualitative and quantitative methods can be used simultaneously to provide complementary mixed-methods perspectives (Palinkas, 2014; Yardley & Bishop, 2007). The survey was designed to take approximately 20-30 minutes. The survey assessed three domains: 1) difficulties in the college setting (e.g., social support, managing emotions, academic difficulty, time management, behavioral problems, etc.); 2) need of postsecondary-based support services; and 3) strengths and assets. One survey destination was used by all informant groups. That is, parents of high school students, parents of postsecondary students, and parents of individuals not currently enrolled in an educational institution were all directed to the same start page. Skip logic was used to ensure that informant-specific questions were administered to the appropriately identified parent-group.

### **Characterization Measures.**

*Autism Spectrum Quotient for Children (AQ; Auyeung, Baron-Cohen, Wheelwright, Allison, 2007).* The AQ is a 50-item parent report questionnaire designed to measure characteristics of ASD in individuals aged 4 and above. The AQ assesses characteristics of ASD and is typically used as a screening tool. Internal consistency for the measure is excellent,  $\alpha = 0.97$  (Auyeung et al., 2007). All items are rated on a 4-point Likert scale (“0 = definitely agree,” “1 = slightly agree,” “2 = slightly disagree,” and “3 = definitely disagree.”) Total scores on the AQ range from 0 to 150 with higher scores representative of more “autistic-like” behavior. A cut off score of 76 is recommended to indicate symptoms in the range of a clinical diagnosis of

ASD. The mean total score for the ASD group exceeded the clinical cutoff and the mean total score for the ADHD group was below the clinical cutoff. Internal consistency for this sample was excellent;  $\alpha = 0.913$  for the overall sample,  $\alpha = 0.859$  for the ADHD group, and  $\alpha = 0.850$  for the ASD group.

***Brief Executive Functioning Measure.*** A brief measure of executive function, modeled after the Barkley Deficits in Executive Functioning-Adult: Other Report Form (BDEFS; Barkley, 2011), was created to assess executive function. The brief executive function measure was a 10-item measure designed to assess parent-reported executive dysfunction in their son or daughter over the past 6 months. Internal consistency for this sample was good,  $\alpha = 0.811$  for the total sample, 0.866 for the ADHD group, and  $\alpha = 0.758$  for the ASD group.

***DSM Level 2- Anxiety-Parent measure.*** The DSM Level 2-Anxiety Parent measure was licensed for use to the lead author by PROMIS Health Organization (See Appendix C for license agreement). The DSM Level 2-Anxiety Parent measure is a brief 10-item measure that assesses anxiety as reported by a parent in children and adolescents. The reliability and validity of this instrument has not been published. Internal consistency for this sample was excellent,  $\alpha = 0.929$ . Although developed for individuals aged 6-17, it was selected for use in this study because it is applicable to our target population and there are few parent-report measures of anxiety that are open-access (for use in an online survey). Parents are asked to report the severity of their son/daughter's anxiety over the past 7 days. Permissions for use were obtained after the ASD survey launched. As such, the anxiety measure was only included in the ADHD online survey.

## **Analyses**

After excluding cases which were out of range or incomplete, data were screened for

careless responding. One validation item (e.g., “Please select ‘B’ for this item”) was the primary means of detecting careless responding. No participants were excluded on the basis of the validation item. Additionally, the minimum response duration (for entire survey) considered to be valid was 2 minutes; seven survey participants finished the survey in less than 2 minutes and were removed from final analyses. Dependent variables within the ASD and ADHD groups were assessed for missing values, shape, and variance. None of the quantitative data contained missing values. However, all qualitative non-responses and responses marked “not applicable” were removed from qualitative analyses. Sample sizes were fairly equitable across groups. Skewness and kurtosis were assessed through a graphic check on normality (Q-Q plot) and the Shapiro-Wilk test. Both were within acceptable limits for the AQ, Executive Functioning measure, and the DSM Level 2- Anxiety-Parent measure. Questions on the online survey were examined independently because the survey in its entirety did not tap a unidimensional construct. In other words, challenges were assessed separate from both needs and strengths. Normality for each of the primary questions on the online survey was within acceptable limits as well. No transformations were needed and the assumptions of the statistical tests were met.

Descriptive statistics were used to characterize participants based on demographic variables and to identify the most reported needs, challenges, and services requested. Descriptive statistics were computed using IBM SPSS Statistics 23. To investigate group differences between parent informant groups, quantitative data from the online survey were analyzed with Multivariate Analysis of Variance (MANOVA). A two-way MANOVA was run with diagnosis group (2: ASD, ADHD) and educational status (3: High School, Postsecondary, and Not Enrolled) as the independent variables. There was insufficient power to examine 2-year vs. 4-year group differences post-hoc. Dependent variables varied by question analyzed and

encapsulated all responses items. For the question assessing student challenges/difficulties, the dependent variables were: self-advocacy, time management, motivation, goals, managing intense emotions, stress associated with school demands, conduct and behavioral issues, attention, managing life tasks, social interactions, social support, managing personal/adaptive skills, other co-occurring psychiatric concerns, taking care of living arrangements, and closeness to family. For the question assessing helpful services in the postsecondary setting, the dependent variables were: transition services, academic tutoring, speech/language services and therapies, assistive technologies, social interaction training, therapy targeting emotion regulation difficulties, weekly supportive therapy or counseling, career counseling, independent living training, study skills and strategies, peer mentoring, frequent check-ins with support staff, facilitated support groups with other students with a shared disability, opportunities to interact socially with other students, and modified living arrangements. Wilks' Lambda was the multivariate test statistic chosen to test the statistical significance of the different effects of the independent variables. If Wilks' Lambda yielded a significant result, post-hoc testing of the effects was conducted.

Statistical significance of the Wilk's Lambda for the omnibus MANOVA was set at  $p < 0.05$ . The  $p$ -value of the multiple comparisons was also set at  $p < 0.05$ . The Bonferroni correction method was considered, to control for the familywise error rate. However, when lowering the  $p$  value to declare a result statistically significant, power greatly reduces and fails to detect false and true effects. Since the final sample was underpowered for this study and yields preliminary data, Bonferroni correction was not applied. There is a lack of consensus on when Bonferroni procedures should be used (Perneger, 1998). Further, many argue that the inflated Type II errors do not justify the use of multiple comparison corrections in preliminary studies (Gelman, Hill, & Yajima; Nakagawa, 2004).

Qualitative text responses were coded by two independent coders. A study-specific coding manual was established and utilized to categorize themes. The coding scheme was developed by the lead author (see White et al., under review) and informed by ASD-specific focus groups and pertinent developmental literature of typically developing students in the postsecondary environment (Chickering & Reisser, 1993) to examine the needs and challenges of students with ASD and ADHD. The Seven Vectors of Student Development (Chickering & Reisser, 1993) was chosen as the theoretical underpinning of the coding scheme because of its demonstrated utility as a model of identity in typically developing college students (Foubert, Nixon, Sisson, & Barnes, 2005). Definitions for each code were created and a coding manual (see Appendix D) was then applied to the full set of interviews. Two independent coders (the lead author and a trained undergraduate researcher) coded 20% of the transcribed focus groups and achieved a reliability Kappa of .77 (i.e., substantial agreement; Landis & Koch, 1977). After agreement at this level was established, one coder independently coded the qualitative survey items.

## **Results**

### **Descriptive Statistics**

Descriptive statistics were computed for all demographic variables of parent respondents and demographic variables of their identified son or daughter. Specifically, demographic variables for parent respondents consisted of sex, ethnicity, race, household income, employment status, number of children, and level of schooling (Table 2). Parent-reported demographic variables for their offspring with ASD or ADHD consisted of chronological age, age of diagnosis, sex, estimated intellectual ability, postsecondary field of study, and whether or not they were involved in their transition IEP (Table 3). The chronological age of the emerging

adult identified with ASD or ADHD ranged from 16-25 and the difference in age between the ASD ( $M = 19.17, SD = 2.41$ ) and the ADHD ( $M = 19.57, SD = 2.79$ ) groups was not significant,  $t(97) = 0.769, p = 0.444$ . The parent-reported diagnosis age of the emerging adult identified with ASD or ADHD ranged from 2-25 and there were significant differences between the ASD ( $M = 8.07, SD = 5.23$ ) and the ADHD ( $M = 11.32, SD = 5.16$ ) groups;  $t(97) = 3.104, p = 0.003$ .

### **Characterization of Sample**

Mean total scores for the characterization measures (AQ, Executive Functioning Measure, and the DSM Level 2- Anxiety-Parent measure) are depicted in Table 4. The ASD and ADHD groups significantly differed on symptoms of ASD,  $t(97) = -8.015, p = 0.001$ . However, the ASD and ADHD groups did not significantly differ on the executive functioning profile,  $t = 0.229, p = 0.820$ . Due to statistical significance on the executive functioning profile and expected differences on ASD symptomatology, neither ASD symptoms nor executive functioning were used as covariates in the analyses. Bivariate correlations among the AQ, Executive Functioning Measure, and DSM- 5 Cross Cutting Anxiety Measure did not yield significance indicating that each measure tapped at different constructs (Table 5).

### **Parent Identified Difficulties and Needed Supports**

**Qualitative Responses.** Two open-ended questions served as the primary items for qualitative data analysis (see Appendix B for the online survey). These included item number 26, “Please describe any other **difficulties or problems** you think your son/daughter is faced with while attending a postsecondary educational institution (or in high-school)” and item number 29, “Please describe any other **services** you think would be **helpful** for your son/daughter attending a postsecondary educational institution.”

For each of these questions (difficulties and services), two primary themes emerged. Code frequency was transformed into an intensity matrix for each group (ASD and ADHD) and each question (challenges and supports). The intensity matrix was used to derive the primary themes from the qualitative items (see Table 6, Table 7, Table 8, Table 9). Due to significant missing data on the qualitative items resulting in uneven subgroups, comparing parent perspectives of individuals with ASD to those of ADHD yielded the most clinically and statistically meaningful results. Parents of individuals with ASD cited social difficulties as principal difficulties for their son or daughter. Specifically, interpersonal competence was cited as the biggest area of difficulty for transition or postsecondary aged individuals with ASD. For the purposes of this study, Interpersonal Competence was defined as listening, cooperating, and communicating effectively. Parents wrote phrases such as, “he gets excited about what the teacher is talking about and interrupts the teacher.” Capacity for intimacy was aggregately rated as the second highest area of difficulty for transition or postsecondary aged individuals with ASD. Capacity for intimacy was defined as the ability to form friendships and long-lasting relationships (platonic or romantic) that endure through crises, distance, and separation. Parents phrased difficulties such as, “[NAME] doesn’t feel the need to have close friends.” Parents of individuals with ADHD differed from parents of individuals with ASD in their top cited difficulties. Specifically, Instrumental Independence (i.e., organizing activities, problem-solving, and time-management) was identified as the primary aggregate difficulty and managing anxiety was listed as the next influential difficulty for their son/daughter.

With respect to desired services in the educational strata, parents of individuals with ASD reported Instrumental Independence as the domain which necessitated the most services and then Interpersonal Competence, which closely followed. The parents of individuals with ADHD

desired distinctly different services, specifically supports to target Inattention and Emotional Independence. Emotional independence for the purposes of this study was defined as separation from parental figures and seeking a support system for emotional or tangible needs.

**Quantitative Responses.** Parents of individuals with ASD and ADHD were asked to identify areas of challenge faced by their son/daughter in the educational arena. Specifically, parents rated self-advocacy, time management, motivation, career and life goals, managing intense emotions, academic stress, behavioral difficulties, attention, managing life tasks and demands, social interactions, social supports, personal and adaptive skills, comorbid psychiatric concerns, taking care of living arrangements, and closeness to family on a 1 to 5 scale based on what they perceived to be challenging for their emerging adult with a disability in the postsecondary setting. Table 10 stratifies the number of participants who rated an option as being a 4 (usually a problem; serious issue) or a 5 (always a problem; severe issue). Social interaction was cited as a top difficulty for parents of individuals with ASD across educational statuses. Parents of emerging adults with ADHD cited time management and attention as top identified challenges.

A two-way MANOVA of the parent-identified difficulties revealed a non-significant interaction between education placement and diagnosis on the combined dependent variables,  $F(30, 158) = 0.768, p = 0.800$ ; Wilks'  $\Lambda = 0.762$ . Educational placement was not a significant predictor,  $F(30, 158) = 1.513, p = 0.055$ ; Wilks'  $\Lambda = 0.603$ . There was a significant main effect for diagnosis,  $F(15, 79) = 4.118, p = 0.001$ ; Wilks'  $\Lambda = 0.561$ . When statistically comparing group differences, parents of individuals with ASD reported greater struggle with self-advocacy [ $F(1, 97) = 4.28, p = 0.025$ ], life tasks [ $F(1, 97) = 5.69, p = 0.019$ ], social interactions [ $F(1, 97) = 23.99, p = 0.001$ ], social support [ $F(1, 97) = 21.45, p = 0.001$ ], adaptive skills [ $F(1, 97) = 5.58,$

$p = 0.020$ ], and living arrangements [ $F(1, 97) = 7.47, p = 0.007$ ], relative to the parents in the ADHD group. Parents of emerging adults with ADHD reported that their son/daughter had difficulties with time management [ $F(1, 97) = 9.36, p = 0.003$ ] and attention [ $F(1, 97) = 15.99, p = 0.001$ ], more so than did the parents in the ASD group.

Parents of individuals with ASD and ADHD were asked to identify services which would be helpful for their son or daughter to receive in a postsecondary setting. Parents rated transition services, academic tutoring, speech/language services and therapies, assistive technologies, social interaction training, therapy targeting emotion regulation difficulties, weekly supportive therapy or counseling, career counseling, independent living training, study skills and strategies, peer mentoring, frequent check-ins with support staff, facilitated support groups with other students with a shared disability, opportunities to interact socially with other students, and modified living arrangements on a 1 to 5 scale based on what they perceived to be a helpful services for their emerging adult with a disability in the postsecondary setting. Table 11 stratifies the number of participants who rated an option as being a 4 (very helpful) or a 5 (extremely helpful). Parents in the ASD group cited opportunities to interact socially with other students as a primary needed service in the postsecondary domain. Parents in the ADHD group indicated career counseling across groups as a primary needed service in the postsecondary placement. Post hoc, differences among the three educational levels were examined (parents of high school students, parents of postsecondary students, and parents of individuals in no educational placement).

A two-way MANOVA of the parent-identified needed supports revealed a non-significant interaction between education placement and diagnosis on the combined dependent variables,  $F(30, 158) = 0.657, p = 0.912$ ; Wilks'  $\Lambda = 0.791$ . There was non-significant main

effect for educational placement,  $F(30, 158) = 1.118, p = 0.321$ ; Wilks'  $\Lambda = 0.680$ . There was a significant main effect for diagnosis,  $F(15, 79) = 4.023, p = 0.001$ ; Wilks'  $\Lambda = 0.567$ . When statistically comparing group differences, parents of individuals with ASD reported that their child would benefit in the postsecondary setting from speech/language services and therapies [ $F(1, 97) = 14.64, p = 0.001$ ], social interaction training [ $F(1, 97) = 22.87, p = 0.001$ ], independent living training [ $F(1, 97) = 22.10, p = 0.001$ ], peer mentoring [ $F(1, 97) = 6.58, p = 0.012$ ], opportunities to interact socially with other students [ $F(1, 97) = 6.31, p = 0.014$ ], and modified living arrangements [ $F(1, 97) = 15.48, p = 0.001$ ] more than parents in the ADHD group did. Parents of an individual with ADHD endorsed academic tutoring [ $F(1, 97) = 7.89, p = 0.006$ ] as a possible service as more helpful/desired than did their ASD counterparts.

**Strengths.** The breakdown of strengths by category is depicted in Table 12. With regards to group differences, parents of individuals with ASD significantly reported that their child was honest [ $F(1, 97) = 4.81, p = 0.031$ ], showed attention to detail [ $F(1, 97) = 5.37, p = 0.001$ ], had genuine interest in learning [ $F(1, 97) = 4.38, p = 0.039$ ], and had little interest in activities that could distract from their studies [ $F(1, 97) = 6.55, p = 0.012$ ], more so than parents of individuals with ADHD did.

**Reasons for not attending a postsecondary educational institution.** Parent-reported reasons for non-enrollment in postsecondary education is detailed in Table 13. There were no significant differences between the ASD and ADHD groups. Parent-reported reasons for discontinuation of postsecondary schooling were not analyzed because participant response on this item ( $n = 2$  for both ASD and ADHD groups) was too small to draw meaningful statistical conclusions.

## Discussion

This study investigated the parent-reported challenges, needed supports, and strengths in a sample of parents with adolescents or young adults with ASD and ADHD. The qualitative and quantitative results suggest that, in the context of transition into postsecondary education, students with ASD primarily struggle with social tasks and skills of daily living. Specifically, in the social domain, parents reported difficulties with social interactions and making and maintaining social supports such as friendships. These findings are consistent with the research marking ASD as a disorder social in nature (American Psychiatric Association, 2013). However, these results are the first to suggest that parents identify social difficulties into adulthood and impairing in the postsecondary domain. The parent-reported struggles with skills of daily living are consistent with past literature indicating that individuals with ASD exhibit relative struggles with independent living (Bal, Kim, Cheong, & Lord, 2015), but are novel in that they characterize a high functioning emerging adult sample. These challenges differed significantly from the parent-identified challenges of emerging adults with ADHD. Specifically, parents of emerging adults with ADHD identified time management and attention as primary difficulties for their son or daughter. This finding is largely consistent with the literature (Cheung et al., 2015) and diagnostic criteria of ADHD (American Psychiatric Association, 2013). However, the lack of parental-reported difficulties with time management and attention among parents of emerging adults with ASD is noteworthy, considering the seemingly identical presentation on the executive functioning measure (see Table 3). The similar executive functioning profile suggests that social impairment is more challenging for emerging adults with ASD than time management.

Despite executive-functioning related concerns not uniformly identified as a primary challenge for their son or daughter with ASD, qualitative results reveal that this is a top area of needed supports for students, followed by social skill competence training. Supports for social skills were endorsed both qualitatively and quantitatively among parents of emerging adults with ASD. The desire for social supports aligns nicely with parental-perceived areas of difficulty. This strongly suggests that interventions designed to target transitioning or postsecondary students with ASD need to encompass social skill training and opportunity.

Parents of emerging adults with both ASD and ADHD identified supports for living outside of the home, both emotional and tangible in nature. These results support the notion that increased independence in the context of identity formation is not unique to psychopathology. Specifically, Chickering and Reisser (1993) identify this as a primary coming of age task that all postsecondary students integrate into their skillset and identity. Future research should determine if there are certain types of independent living supports that are unique to emerging adults with ASD or ADHD.

The extant research on individuals with ASD primarily centers on deficits and needed areas of improvement through evidence-based intervention. In addition to evaluation of challenges, this study also sought to determine unique strengths specific to emerging adults with ASD. Honesty and attention to studies and detail prove to be strengths identified by parents of emerging adults with ASD, moreso than by parents of emerging adults with ADHD. Future research should identify emerging adult identified strengths to examine comparisons across informant groups. Identifying group-specific strengths has vast implications for the development of evidence-based intervention. Specifically, integrating strengths into the manualized intervention could help foster compliance and engagement.

## **Limitations**

There are several limitations to note in this study. First, the total sample ( $n = 99$ ) was relatively small and the study was therefore not powered to detect differences among all six informant groups. Our recruitment efforts were stringent, specifically targeting age-appropriate and psychologically-related sources. This recruitment process, while reflecting a possible strength in participant characterization, may not have been reflective of the wider/more representative sample at large. Future research examining parental-reported challenges, needed supports, and strengths should employ sufficiently large sample sizes so that finer grain comparisons can be made. For example, larger sample sizes would allow for secondary and postsecondary comparisons, not just examination of ASD and ADHD.

Another potential limitation was the design of the study. All of the data came from a single source (parent-report) and modality (online survey). Further, all responses were collected at a single point in time. Future studies should integrate multiple face-to-face sessions with several respondents in order to establish stability and input from multiple stakeholders. In-person sessions may also mitigate any potential SES-effect due to only offering the initial survey on an online platform. SES should also be examined within the context of parental responses. The sample, particularly among parents of a child with ADHD, was highly affluent.

The sample of individuals who chose to complete a survey online may also be a limitation of the study, as individuals who volunteered to complete the survey may not be representative of those in the community at large. Further, only acquiring parental informants may offer biased opinions about the true challenges, needs, and strengths of emerging adults with ASD and ADHD. Likewise, the parent informants only reported that their son or daughter had a confirmed diagnosis of ASD or ADHD. However, these diagnoses were not confirmed by a

member of the study team. Anecdotally, a few parents emailed the study coordinator to inquire about taking the survey if their child “only” had ADD or Asperger’s. Perhaps differing language with regards to clinical diagnoses influenced the parents who responded to the online survey.

### **Recommendations for Further Research**

Despite an increase in the number of students with ASD enrolled in universities (White et al., 2011), there is a dearth of research on the types of challenges they face or needs related to transition that they have. The findings presented herein may inform future transition-based structured programming aimed to address the needs of young adults with ASD in the college environment. The primary needs and challenges faces by students with ASD, as identified by their parents, relate to social skills training and opportunity, emotional and tangible independence training, and self-advocacy-related skills. These needs should be targeted in the context of support and intervention programs in order to promote academic and social success in higher education for students with ASD.

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Table 1

*Participant Sample*

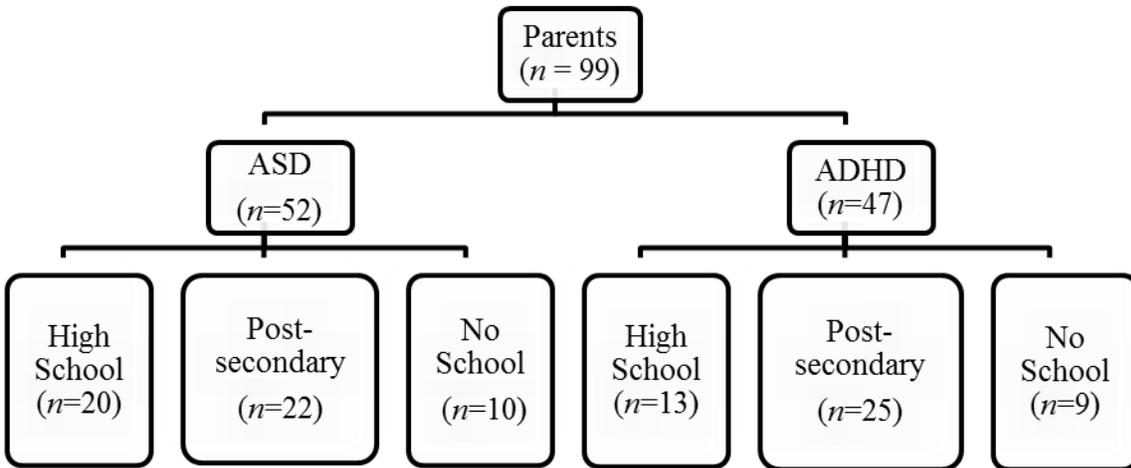


Table 2

*Demographic Characteristics of Parent Participants (n = 99).*

<b>Demographic</b>	<b>ASD (n = 52)</b>	<b>ADHD (n = 47)</b>
Males (%)	9.62	8.51
Ethnicity (%)		
American Indian or Alaska Native	0	0
Asian	3.85	2.13
Black or African American	15.39	0
Native Hawaiian or Other Pacific Islander	1.92	0
White	71.15	93.62
Other	3.85	0
Prefer not to indicate	3.85	4.26
Hispanic or Latino (%)	7.70	8.51
Age Range (%)		
20-30	1.92	0
31-40	3.85	8.51
41-50	40.38	31.91
51-60	50.00	53.19
61-70	3.85	6.38
Household Income (%)		
Less than \$25,000	7.69	0
\$25,000 to \$49,999	23.08	10.64
\$50,000 to \$99,999	30.77	21.28
\$100,000 or more	38.46	68.09
Employed outside of the home (%)	71.15	74.47
Number of children ( <i>M, SD</i> )	2.46 (1.23)	2.47 (1.10)
Highest level of schooling		
Middle school	1.92	0
High school (diploma or GED)	0	2.13
Some college/technical school	21.15	12.77
Bachelor's/4-year college degree	36.54	44.68
Graduate school (Master's degree or above)	40.38	40.43

Table 3

*Demographic Characteristics of Respondent Son or Daughter (n = 99).*

<b>Demographic</b>	<b>ASD (n = 52)</b>	<b>ADHD (n = 47)</b>
Chronological Age ( <i>M, SD</i> )	19.17 (2.41)	19.57 (2.79)
Age of Diagnosis ( <i>M, SD</i> )	8.07 (5.23)	11.32 (5.16)
Males (%)	76.92	68.09
Estimated Intellectual Ability (%)		
Above Average/Intellectually Gifted	46.15	51.06
Intellectually Average	26.92	44.68
Below Average	26.92	4.26
Participation in Transition IEP (%)	13.5	8.51
<b>Demographic</b>	<b>ASD (n = 22)</b>	<b>ADHD (n = 25)</b>
Postsecondary Schooling (%) <sup>a</sup>		
Science	4.55	20.00
Engineering	9.09	12.00
Computer Science	9.09	4.00
Social Science	13.64	16.00
Business	4.55	20.00
Language Arts	18.18	0
Creative Arts	4.55	0
Technical/Trade	4.55	0
Other	45.45	40.00

*Postsecondary Schooling<sup>a</sup>: Participants were allowed to choose more than one option for this item*

Table 4

*Descriptive Measure Data*

	ASD ( <i>M, SD</i> )	ADHD ( <i>M, SD</i> )	P-value of pairwise comparison
Total AQ Score	92.08 (16.16)	64.77 (17.75)	.001*
Total EF Score	25.96 (5.02)	26.23 (6.67)	.820
DSM-5 Anxiety Score	--	24.09 (8.84)	--

\*p &lt; 0.05

Table 5

*Bivariate Correlations among Measures*

	1	2	3
1. AQ	--	0.162	-0.039
2. EF Measure	0.162	--	0.101
3. DSM 5 Cross Cutting Anxiety	-0.039	0.101	--

Table 6

*Intensity Matrix of the Frequency of Codes within Each Category Identified on “Difficulties or Problems” Item*

		Number of endorsements by participant type			
<b>ASD</b>		Parent of HS	Parent of Postsecondary	Not enrolled	Total
Developing Competence	Intellectual competence	3	0	0	3
	Interpersonal competence	1	7	2	10
	Physical and manual competence	0	0	0	0
Managing Emotions	Anxiety	1	1	1	3
	Persistence	0	0	0	0
	Frustration	0	0	0	0
	Depression	0	0	0	0
	Overwhelmed	1	0	1	2
	Inattention	0	0	0	0
Moving Through Autonomy	Emotional independence	1	1	0	2

	Instrumental independence	1	2	0	3
	Motivation	2	0	0	2
	Responsibility	0	2	0	2
Developing Mature Interpersonal Relationships	Toleration of Differences	0	1	1	2
	Capacity for intimacy	4	2	1	7
Establishing Identity	Self-Concept	0	1	1	2
	Stability	1	0	1	2
Developing Purpose	Vocational plans and aspirations	0	0	0	0
	Personal interests	2	1	0	3
	Interpersonal and family commitments	0	0	0	0
Developing Integrity	Values	0	0	0	0
Other	Keeping up with the pace	0	1	0	1

Taking risks	0	0	0	0
Physical space	1	0	0	1
Substance Abuse	0	0	0	0
Prescription Medication	0	2	0	2
Decision-making	0	0	0	0
Transportation	0	2	0	2
Non-intentional Forgetting	0	0	0	0
Totals	18	23	8	49

Table 7

*Intensity Matrix of the Frequency of Codes within Each Category Identified on “Difficulties or Problems” Item*

		Number of endorsements by participant type			
<b>ADHD</b>		Parent of HS	Parent of Postsecondary	Not enrolled	Total
Developing Competence	Intellectual competence	0	0	0	0
	Interpersonal competence	1	1	0	2
	Physical and manual competence	0	0	0	0
Managing Emotions	Anxiety	0	5	1	6
	Persistence	0	0	0	0
	Frustration	0	0	0	0
	Depression	0	3	0	3
	Overwhelmed	1	0	1	2
	Inattention	0	2	2	4
Moving Through Autonomy	Emotional independence	0	0	0	0

	Instrumental independence	2	4	2	8
	Motivation	0	1	0	1
	Responsibility	0	0	0	0
Developing Mature Interpersonal Relationships	Toleration of Differences	1	0	0	1
	Capacity for intimacy	0	1	0	1
Establishing Identity	Self-Concept	2	0	1	3
	Stability	0	0	0	0
Developing Purpose	Vocational plans and aspirations	1	0	0	1
	Personal interests	0	0	0	0
	Interpersonal and family commitments	0	0	0	0
Developing Integrity	Values	0	0	0	0
Other	Keeping up with the pace	0	0	0	0

Taking risks	0	3	1	4
Physical space	0	0	0	0
Substance Abuse	0	0	3	3
Prescription Medication	1	0	1	2
Decision-making	0	0	1	1
Transportation	0	0	0	0
Non-intentional Forgetting	1	1	0	2
Totals	10	21	13	44

Table 8

*Intensity Matrix of the Frequency of Codes within Each Category Identified on “Supports” Item*

		Number of endorsements by participant type			
<b>ASD</b>		Parent of HS	Parent of Postsecondary	Not enrolled	Total
Developing Competence	Intellectual competence	2	0	2	4
	Interpersonal competence	0	4	1	5
	Physical and manual competence	0	0	0	0
Managing Emotions	Anxiety	1	0	0	1
	Persistence	0	0	0	0
	Frustration	0	0	0	0
	Depression	0	0	0	0
	Overwhelmed	0	0	0	0
	Inattention	0	0	0	0
Moving Through Autonomy Toward Interdependence	Emotional independence	2	2	0	4
	Instrumental	2	5	1	8

	independence				
	Motivation	1	0	0	1
	Responsibility	0	0	0	0
Developing Mature Interpersonal Relationships	Toleration of Differences	1	0	0	1
	Capacity for intimacy	0	0	0	0
Establishing Identity	Self-Concept	0	0	0	0
	Stability	1	0	0	1
Developing Purpose	Vocational plans and aspirations	1	0	0	1
	Personal interests	2	0	0	2
	Interpersonal and family commitments	0	0	0	0
Developing Integrity	Values	0	0	0	0
Other	Keeping up with the pace	1	2	0	3
	Taking risks	0	0	0	0

Physical space	0	0	0	0
Substance Abuse	0	0	0	0
Prescription Medication	0	0	0	0
Decision-making	0	0	0	0
Transportation	0	2	0	2
Non-intentional Forgetting	0	0	0	0
<b>Totals</b>	<b>14</b>	<b>15</b>	<b>4</b>	<b>33</b>

Table 9

*Intensity Matrix of the Frequency of Codes within Each Category Identified on “Supports” Item*

		Number of endorsements by participant type			
<b>ADHD</b>		Parent of HS	Parent of Postsecondary	Not enrolled	Total
Developing Competence	Intellectual competence	0	0	0	0
	Interpersonal competence	0	0	0	0
	Physical and manual competence	0	0	0	0
Managing Emotions	Anxiety	0	0	0	0
	Persistence	0	0	0	0
	Frustration	0	0	0	0
	Depression	0	0	0	0
	Overwhelmed	0	1	0	1
	Inattention	1	1	1	3
Moving Through Autonomy Toward Interdependence	Emotional independence	2	1	1	4
	Instrumental	0	1	1	2

	independence				
	Motivation	0	0	0	0
	Responsibility	0	0	1	1
Developing Mature Interpersonal Relationships	Toleration of Differences	0	0	0	0
	Capacity for intimacy	0	0	0	0
Establishing Identity	Self-Concept	0	0	1	1
	Stability	0	0	0	0
Developing Purpose	Vocational plans and aspirations	0	0	0	0
	Personal interests	0	0	0	0
	Interpersonal and family commitments	0	0	0	0
Developing Integrity	Values	0	0	0	0
Other	Keeping up with the pace	0	0	0	0
	Taking risks	0	0	0	0

Physical space	0	0	0	0
Substance Abuse	0	0	0	0
Prescription Medication	0	1	0	1
Decision-making	0	0	0	0
Transportation	0	0	1	1
Non-intentional Forgetting	0	0	0	0
<b>Totals</b>	<b>3</b>	<b>5</b>	<b>6</b>	<b>14</b>

Table 10

*Greatest Parent-Identified Difficulties*

ASD (n = 52)			ADHD (n = 47)		
	Challenge	n (%)		Service	n (%)
ASD Postsecondary (n = 22)	1. Social Interaction	15 (68.2%)	ADHD Postsecondary (n = 25)	1. Stress associated with school demands	15 (60.0%)
	2. Self-Advocacy	14 (63.6%)		2. Time management	14 (56.0%)
	3. Managing Intense Emotions	13 (59.0%)		3. Attention	13 (52.0%)
ASD High School (n = 20)	1. Social Interaction	14 (70.0%)	ADHD High School (n = 13)	1. Attention	10 (76.9%)
	2. Social Supports	10 (50.0%)		2. Time Management	7 (53.8%)
	3. Goals	9 (45.0%)		2. Managing intense emotions	7 (53.8%)
ASD Not enrolled (n = 10)	1. Goals	6 (60.0%)	ADHD Not enrolled (n = 9)	1. Attention	7 (77.8%)
	2. Stress associated with school demands	5 (50.0%)		2. Time Management	6 (66.7%)
	2. Social Interactions	5 (50.0%)		2. Stress associated with school demands	6 (66.7%)
	2. Social Support	5 (50.0%)		3. Managing intense emotions	5 (55.6%)

Table 11

*Most Parent-Identified Needed Services*

<b>ASD (n = 52)</b>		<b>ADHD (n = 47)</b>	
Challenge	<i>n</i> (%)	Service	<i>n</i> (%)
ASD Postsecondary ( <i>n</i> = 22)	1. Emotion Regulation	ADHD Postsecondary ( <i>n</i> = 25)	1. Academic tutoring
	Therapy		2. Study Skills and Strategies
	2. Social interaction training		3. Career Counseling
	2. Transition services		
	2. Weekly supportive therapy		
	2. Career counseling		
ASD High School ( <i>n</i> = 20)	2. Peer mentoring	ADHD High School ( <i>n</i> = 13)	1. Career Counseling
	2. Opportunities to interact socially with other students		1. Facilitated support groups for other students with a disability
	1. Transition Services		
	2. Opportunities to interact socially		
	3. Career counseling		

	3. Independent living training	14 (70.0%)			
	3. Frequent check-ins with support staff	14 (70.0%)			
ASD Not enrolled ( <i>n</i> = 10)	1. Independent living training	8 (80.0%)	ADHD Not enrolled ( <i>n</i> = 9)	1. Weekly supportive therapy or counseling	6 (66.7%)
	1. Peer mentoring	8 (80.0%)		1. Study skills or strategies	6 (66.7%)
	1. Facilitated support groups with other students with a disability	8 (80.0%)		1. Opportunities to interact socially with other students	6 (66.7%)
	1. Opportunities to interact socially with other students	8 (80.0%)		2. Career counseling	5 (55.6%)
				2. Frequent check-ins with support staff	5 (55.6%)

Table 12

*Parent Identified Strengths*

	<b>ASD (%; n =52)</b>	<b>ADHD (%; n = 47)</b>	<b>P-value of pairwise comparison</b>
Honesty	84.61	65.96	0.031*
Attention to detail	63.46	17.02	0.001*
Academic persistence	38.46	42.55	0.682
Strong organizational skills	19.23	10.64	0.238
Genuine interest in learning	65.38	44.68	0.039*
Curiosity	73.08	68.09	0.590
Dedication to chosen field of study	51.92	46.81	0.754
Little interest in activities that could distract from studies	19.23	2.13	0.012*
Resilience (i.e., the ability to recover from setbacks)	32.69	44.68	0.102
Loyalty	63.46	78.72	0.098
Superior intellectual skills	38.46	44.68	0.535

*Note: Participants were allowed to choose more than one option for this item*

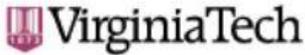
\*p < 0.05

Table 13

*Decision to Not Enroll in Postsecondary Schooling*

	<b>ASD (M, SD) n = 8</b>	<b>ADHD (M, SD) n = 10</b>	<b>P-value of pairwise comparison</b>
Is not sure what (s)he wants to do with their life	2.20 (1.317)	2.00 (1.195)	0.743
Tried attending college but dropped out or left because s/he was struggling academically	1.20 (0.632)	2.00 (1.852)	0.217
Tried attending college but left because s/he was struggling for non-academic reasons	1.40 (1.265)	2.00 (1.852)	0.426
Tried attending college but was dismissed or forced to leave for academic reasons	1.00 (0)	1.63 (1.188)	0.113
Tried attending college but was dismissed or forced to leave for non-academic reasons	1.00 (0)	1.25 (0.707)	0.276
Tried attending college but dropped out or left because it was too expensive	N/A	N/A	N/A
Decided to get a job instead of going to school	2.20 (1.398)	2.88 (1.885)	0.395
Felt like s/he couldn't do well in school	2.10 (1.663)	2.00 (1.195)	0.888

*Note: Participants were allowed to choose more than one option for this item*



**Office of Research Compliance**  
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**MEMORANDUM**

**DATE:** May 22, 2015  
**TO:** Susan Williams White, Rebecca Marie Elias  
**FROM:** Virginia Tech Institutional Review Board (FWA00000572, expires April 25, 2018)  
**PROTOCOL TITLE:** Identifying the Needs of College Students with ASD  
**IRB NUMBER:** 14-181

Effective May 22, 2015, the Virginia Tech Institutional Review Board (IRB) Chair, David M Moore, approved the Continuing Review request for the above-mentioned research protocol.

This approval provides permission to begin the human subject activities outlined in the IRB-approved protocol and supporting documents.

Plans to deviate from the approved protocol and/or supporting documents must be submitted to the IRB as an amendment request and approved by the IRB prior to the implementation of any changes, regardless of how minor, except where necessary to eliminate apparent immediate hazards to the subjects. Report within 5 business days to the IRB any injuries or other unanticipated or adverse events involving risks or harms to human research subjects or others.

All investigators (listed above) are required to comply with the researcher requirements outlined at:

<http://www.irb.vt.edu/pages/responsibilities.htm>

(Please review responsibilities before the commencement of your research.)

**PROTOCOL INFORMATION:**

Approved As: **Expedited, under 45 CFR 46.110 category(ies) 5,6,7**  
Protocol Approval Date: **June 2, 2015**  
Protocol Expiration Date: **June 1, 2016**  
Continuing Review Due Date\*: **May 18, 2016**

\*Date a Continuing Review application is due to the IRB office if human subject activities covered under this protocol, including data analysis, are to continue beyond the Protocol Expiration Date.

**FEDERALLY FUNDED RESEARCH REQUIREMENTS:**

Per federal regulations, 45 CFR 46.103(f), the IRB is required to compare all federally funded grant proposals/work statements to the IRB protocol(s) which cover the human research activities included in the proposal / work statement before funds are released. Note that this requirement does not apply to Exempt and Interim IRB protocols, or grants for which VT is not the primary awardee.

The table on the following page indicates whether grant proposals are related to this IRB protocol, and which of the listed proposals, if any, have been compared to this IRB protocol, if required.

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## Appendix B. Online Survey

### **Identifying the Needs, Challenges, and Strengths of Post-Secondary Students with ADHD**

*An anonymous online survey*

#### **Investigators**

Principal Investigator: Dr. Susan W. White

Co-Investigators: Rebecca Elias

#### **Purpose and Procedure**

The purpose of this research study is to develop a better understanding of the needs and strengths of students who are diagnosed with a Attention Deficit Hyperactivity Disorder (ADHD). We invite you to complete this online survey if you are:

1. A parent of an adolescent or adult with ADHD (if your son/daughter with ADHD is between the ages of 16 and 25, regardless of whether or not your son/daughter is in college)

If you choose to participate in this research study, you will be asked to complete an online survey. We ask that you read this consent form and take careful consideration when answering each of the items within the survey. Total time to complete the survey is about 40 minutes.

If you need to stop the survey before you are complete and you want to save your work, so you can go back later and finish it, please click on the bar at the top of the screen. This will allow you to return to the survey at the point that you left off. The link you were sent for this survey is unique and can be used only one time.

Because some individuals attempt to exploit surveys (for example, by taking a survey repeatedly for reimbursement), we reserve the right to try to determine the validity of any individuals requesting or completing this survey. If we think an individual is suspicious for any reason, we may request, via email, a callback phone number and reimbursement may be withheld until we can confirm the legitimacy of the individual (in other words, that the person completed only one survey). If it is determined that a person completed the survey fraudulently (e.g., multiple times, or using aliases) we reserve the right to seek legal consultation and pursue investigation. Furthermore, this survey is limited only to individuals located in the United States.

#### **Risks**

One possible risk is experiencing discomfort or anxiety while completing the survey. You may stop the survey at any time and participation in future research will not be jeopardized. At the end of the survey, we provide some online resources and service agencies. While some of the agencies listed provide services free of charge, some do charge for services. If you choose to seek treatment from a provider who does charge for the services, it is your responsibility to pay

for these services.

### Benefits

There is no immediate, direct, or indirect benefit to you for participating in this study. However, we hope that results of this project can help in designing services to benefit students.

### Compensation

When you complete this survey, you will receive a \$5 electronic gift card for participation.

### Confidentiality

Your e-mail address is collected at the end of the survey and will be used solely for the purpose of sending the electronic gift card. We will match the email address you provide at the end of the survey to the one that requested the survey to provide the gift card. Please use the same address, so we send the card to the right person. We are doing this prevent robot responses. The answers you give in this study will not be linked to any personally identifying information. Your e-mail address will be stored separately from your survey answers. Subject numbers will be assigned for data storage, and personal information (i.e., e-mail address) will not be associated with the subject number. As such, all of your answers will be kept *strictly confidential and anonymous*. Only the principal investigator of this study and a trained research assistant will have access to the list of participants' email addresses (without a link to survey answers).

It is possible that the Institutional Review Board (IRB) may view this study's collected data for auditing purposes. The IRB is responsible for the oversight of the protection of human subjects involved in research. If you would like to contact the graduate students conducting this study or their advisor, you are welcome to do so. Contact information is at the bottom of this page.

You do not have to participate in this survey and, if you choose to participate, you can stop at any time. Please note that if you wish to receive the gift card, you need to get to the end of the survey and enter the same email address you used to request the survey link. We do ask that you try to answer every question completely to the best of your ability.

### Subject's Responsibilities

As a voluntary participant in this study, you have the following responsibilities:

1. Complete the questions to the best of your ability.
2. Contact the researchers if you have any questions about the study.

### Questions

If you have any questions about the protection of human research participants regarding this study, you may contact Dr. David Moore, Chair Virginia Tech Institutional Review Board for the Protection of Human Subjects, telephone: (540) 231-4991; e-mail: [moored@vt.edu](mailto:moored@vt.edu); address: Office of Research Compliance, 2000 Kraft Drive, Suite 2000 (0497), Blacksburg, VA 24060 or

David W. Harrison, PhD, Chair Departmental Institutional Review Board, telephone: (540) 231-4422 ; e-mail: [dwh@vt.edu](mailto:dwh@vt.edu)

If you would like to speak with a member of this research team, please call Dr. Susan White at the Child Study Center at (540) 231-8276 or e-mail: [relias@vt.edu](mailto:relias@vt.edu). Before continuing on to the survey, we ask that you please print a copy of this form for your records (Ctrl + P).

By entering your name below and continuing to the survey, you acknowledge that you have read this document and that you voluntarily consent to participate in this study.\*

**Page exit logic:** Page Logic**IF:** Question "Are you the parent or guardian of a son or daughter with Attention Deficit/Hyperactivity Disorder (ADHD)?" #1 is one of the following answers ("No") **THEN:** Jump to [page 15 - Disqualification Page-ADHD](#)

**1) Are you the parent or guardian of a son or daughter with Attention Deficit/Hyperactivity Disorder (ADHD)?\***

- Yes
- No

**Page exit logic:** Page Logic**IF:** Question "Are you the parent or guardian of a son or daughter with autism or an autism spectrum disorder (e.g. Asperger's disorder, PDD-NOS)?" #2 is one of the following answers ("Yes") **THEN:** Jump to [page 17 - Disqualification Page-ADHD and ASD](#)

**2) Are you the parent or guardian of a son or daughter with autism or an autism spectrum disorder (e.g. Asperger's disorder, PDD-NOS)?\***

- Yes
- No

**3) What age was your son / daughter diagnosed by a professional? (NOTE: If you have more than one child with an ADHD diagnosis, please select, for the purpose of this survey, only your oldest child who is between the ages of 16-25)\***

**Page exit logic:** Page Logic**IF:** Question "Please indicate your son/daughter's current age in years:" #4 is one of the following answers ("Younger than 16", "Older than 25") **THEN:** Jump to [page 16 - Disqualification Page-Age](#)

**4) Please indicate your son/daughter's current age in years:\***

**Please answer the following questions about your son/daughter with ADHD. If you have more than one child with ADHD who is between the ages of 16 and 25, please answer the questions related to the older child in this age-range.**

**5) Please indicate your son/daughter's gender:\***

- Male
- Female

Other (e.g., transgender)

**6) Did your son/daughter (or does s/he currently) receive services via an Individualized Education Plan (IEP) or 504 Accommodation plan for one of the following disability categories?**

ASD

Deaf-Blindness

Deafness

Emotional Disturbance

Hearing Impairment

Intellectual Disability

Multiple Disabilities

Orthopedic Impairment

Other Health Impairment

Specific Learning Disability

Speech or Language Impairment

Traumatic Brain Injury

Visual Impairment, including Blindness

Other: \_\_\_\_\_

**Logic: Show/hide trigger exists.**

**7) Please select one of the following that best describes your son/daughter's current academic status.\***

Enrolled in high school (including home-schooling)

Enrolled in 2-year college

Enrolled in 4-year college or university

Enrolled in a technical, trade, or vocational school

Enrolled in military training or are active military personnel

Enrolled in graduate school

Not in formal schooling of any type

**Logic: Hidden unless: Question "Please select one of the following that best describes your son/daughter's current academic status." #7 is one of the following answers ("Enrolled in high school (including home-schooling)")**

**8) You indicated that your son/daughter is currently in high-school. What would your son/daughter like to do immediately after graduating from high-school?\***

Go to a 2-year college

Go to a 4-year college or university

Go to a technical/trade school

Get a job

Join the military

Undecided

Other - Please describe:: \_\_\_\_\_

**Logic: Hidden unless: Question "Please select one of the following that best describes your son/daughter's current academic status." #7 is one of the following answers ("Enrolled in high school (including home-schooling)")**

**9) Is your son/daughter actively participating in the transition process from secondary/high school?\***

Yes

No

**Logic: Hidden unless: Question "Please select one of the following that best describes your son/daughter's current academic status." #7 is one of the following answers ("Enrolled in 2-year college", "Enrolled in 4-year college or university", "Enrolled in a technical, trade, or vocational school", "Enrolled in military training or are active military personnel", "Enrolled in graduate school")**

**10) You indicated that your son/daughter is currently in some type of college or post-secondary program, or in the military. Please indicate your son/daughter's academic major or field of study. If your son / daughter has more than one major, mark all that apply.\***

Science (e.g., physics, chemistry)

Engineering (e.g., mechanical engineering)

Computer science (including IT)

Social sciences (e.g., economics, psychology)

Business (e.g., marketing, accounting)

Language Arts (e.g., journalism)

Creative Arts (e.g., graphic design, painting, film)

Technical/trades (e.g., automotive, construction)

Other - Please describe:: \_\_\_\_\_

**Logic: Hidden unless: Question "Please select one of the following that best describes your son/daughter's current academic status." #7 is one of the following answers ("Enrolled in 2-year college", "Enrolled in 4-year college or university", "Enrolled in a technical, trade, or vocational school", "Enrolled in military training or are active military personnel", "Enrolled in graduate school")**

**11) Did your son/daughter participate in the Transition IEP process from high school to their postsecondary institution?\***

Yes

No

**Logic: Hidden unless: Question "Please select one of the following that best describes your son/daughter's current academic status." #7 is one of the following answers ("Not in formal schooling of any type")**

12) You indicated that your son/daughter is currently not in any type of formal post-secondary education program. Would your son/daughter like to be enrolled in college, a university, or other post-secondary school?\*

- Yes
- No
- Not sure

**Logic: Hidden unless: Question "Please select one of the following that best describes your son/daughter's current academic status." #7 is one of the following answers ("Enrolled in 2-year college", "Enrolled in 4-year college or university", "Enrolled in a technical, trade, or vocational school", "Enrolled in graduate school")**

13) How did your son/daughter choose his/her postsecondary institution? Please rank each of the following, from 1 (least important) to 5 (with 5 being the most serious or important consideration).

- \_\_\_\_\_ Location (i.e. close to family)
- \_\_\_\_\_ Academic reputation
- \_\_\_\_\_ Supports for students with disabilities
- \_\_\_\_\_ Cost
- \_\_\_\_\_ Personal match (e.g., school size, diversity, resource availability)

**Logic: Show/hidden trigger exists. Hidden unless: Question "Please select one of the following that best describes your son/daughter's current academic status." #7 is one of the following answers ("Not in formal schooling of any type")**

14) Has your son/daughter ever been enrolled in a 2-year or 4-year college, or a technical school, for more than four weeks?\*

- Yes
- No

**Logic: Hidden unless: Question "Has your son/daughter ever been enrolled in a 2-year or 4-year college, or a technical school, for more than four weeks?" #14 is one of the following answers ("Yes")**

15) Please indicate how long your son/daughter was enrolled (in weeks) at:\*

- A 2-year college:: \_\_\_\_\_
- A 4-year college:: \_\_\_\_\_
- A technical, trade, or vocational school: \_\_\_\_\_

**Logic: Hidden unless: Question "Has your son/daughter ever been enrolled in a 2-year or 4-year college, or a technical school, for more than four weeks?" #14 is one of the following answers ("Yes")**

16) Why did your son/daughter discontinue postsecondary schooling (choose all that apply)?\*

- Inadequate support systems (e.g., lack of friends, other relationships, or services)
- Financial constraints
- Difficulty with academic rigor

- Lack of motivation
- Inadequate organizational skills
- Social problems/challenges
- Was not a "fit" for interests
- Other - Please describe: \_\_\_\_\_

**Logic: Hidden unless: Question "Please select one of the following that best describes your son/daughter's current academic status." #7 is one of the following answers ("Not in formal schooling of any type")**

**17) Please rate each of the following reasons based on how applicable it was to your son/daughter's decision not to be enrolled in school, from 1 to 5. My son/daughter:\***

	1 (not applicable)	2 (slightly applicable)	3 (somewhat applicable)	4 (very applicable)	5 (absolutely applicable)
is not sure what (s)he wants to do with their life.	()	()	()	()	()
tried attending college but dropped out or left because s/he was struggling academically.	()	()	()	()	()
tried attending college but left because s/he was struggling for non-academic reasons.	()	()	()	()	()
tried attending college but was dismissed or forced to leave for academic reasons	()	()	()	()	()

tried attending college but was dismissed or forced to leave for non-academic reasons.	<input type="checkbox"/>				
tried attending college but dropped out or left because it was too expensive.	<input type="checkbox"/>				
decided to get a job instead of going to school.	<input type="checkbox"/>				
felt like s/he couldn't do well in school.	<input type="checkbox"/>				

**Logic: Show/hide trigger exists.**

**18) Is your son / daughter currently employed?\***

- Yes, full-time (32 or more hours a week)
- Yes, part-time
- No

**Logic: Hidden unless: Question "Is your son / daughter currently employed?" #18 is one of the following answers ("Yes, full-time (32 or more hours a week)", "Yes, part-time")**

**19) Did your son / daughter receive assistance in obtaining this job (i.e. supported employment, vocational rehabilitation, school employment specialist, family, friend, or other referral, etc.)?\***

- Yes
- No

**20) From the list below, please indicate all types of therapies and services your son/daughter has received during their academic career. This includes any services provided by your child's school, services you have secured and provided for, and any other**

**such services. If you marked that a service was received, please specify the age when he/she first began receiving this service.**

	Received Service?	Age when first received?			
	Option 1	Younger than 5 years old	5 to 10 years old	11 to 15 years old	Older than 15
Occupational therapy	<input type="checkbox"/>				
Anger management training	<input type="checkbox"/>				
Psychotropic medications (e.g., to manage anxiety, to decrease aggression)	<input type="checkbox"/>				
Applied behavioral analysis (including discrete trial training)	<input type="checkbox"/>				
Social skill intervention	<input type="checkbox"/>				
Individual therapy or counseling	<input type="checkbox"/>				
Intensive early educational programming	<input type="checkbox"/>				
Floor-time	<input type="checkbox"/>				
Academic accommodations	<input type="checkbox"/>				
Speech and language therapy	<input type="checkbox"/>				
Training in independent living skills	<input type="checkbox"/>				

**21) During high school, was (is) your son/daughter enrolled in any the following class types (please select all that apply):\***

Special education resource room

- Counseling
- General education
- Advanced placement class
- Not enrolled in any of these types of classes

**Logic: Show/hide trigger exists.**

**22) Does your child have any siblings who are currently attending a postsecondary institution?\***

- Yes
- No

**Logic: Hidden unless: Question "Does your child have any siblings who are currently attending a postsecondary institution?" #22 is one of the following answers ("Yes")**

**23) Do any of these siblings have a recognized disability?\***

- Yes
- No

**24) Does your child have any siblings who completed a degree or certificate from a postsecondary program?\***

- Yes
- No

**25) Please rate each of the following areas of possible difficulty, from 1 to 5. Make your ratings for each area based on what you perceive to be challenging for your son/daughter with a disability in the post-secondary or college setting. If your child is not in college right now, base your answers on what you have seen in high-school or other educational settings.\***

	1 (never a problem)	2 (rarely a problem; mild issue)	3 (sometimes a problem; moderate issue)	4 (usually a problem; serious issue)	5 (always a problem; severe issue)
Self-advocacy (speaking up for him/herself, letting others know what s/he needs)	()	()	()	()	()
Time management (e.g., missing due dates)	()	()	()	()	()

Motivation (e.g., does not see the point in doing certain things in school)	( )	( )	( )	( )	( )
Goals (e.g., lack of clear educational goals)	( )	( )	( )	( )	( )
Managing intense emotions (e.g., emotion control/regulation)	( )	( )	( )	( )	( )
Stress associated with school demands	( )	( )	( )	( )	( )
Conduct and behavioral issues (e.g., violating others' rights)	( )	( )	( )	( )	( )
Attention (e.g., not maintaining focus or attention in class)	( )	( )	( )	( )	( )
Managing life tasks (e.g., poor time management, organization difficulties, getting to class)	( )	( )	( )	( )	( )
Social interactions (e.g., difficulties making friends)	( )	( )	( )	( )	( )
Social support (e.g., lonely, isolated)	( )	( )	( )	( )	( )

Managing personal/adaptive skills (e.g., deficient personal hygiene, managing money, other independent living skills)	( )	( )	( )	( )	( )
Other co-occurring psychiatric concerns (e.g., anxiety disorders, depression)	( )	( )	( )	( )	( )
Taking care of living arrangements (e.g., paying bills/rent)	( )	( )	( )	( )	( )
Closeness to family (e.g., feeling homesick, missing family)	( )	( )	( )	( )	( )

**26) Please describe any other difficulties or problems you think your son/daughter is faced with while attending a postsecondary educational institution (or in high-school).**

\_\_\_\_\_

**27) Please think back to supports, services, and therapies your son/daughter may have had/currently have in high school. For each of the types of services below, please indicate how helpful each was in preparing him/her for college and transition to independent adulthood.\***

	<i>Never had this service</i>	1 (not helpful)	2 (slightly helpful)	3 (moderately helpful)	4 (very helpful)	5 (extremely helpful)
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Transition services (to help with the transition to postsecondary education)	( )	( )	( )	( )	( )	( )
Academic tutoring	( )	( )	( )	( )	( )	( )
Speech/language services and therapies	( )	( )	( )	( )	( )	( )
Assistive technologies	( )	( )	( )	( )	( )	( )
Social interaction training (e.g., how to make and keep friends)	( )	( )	( )	( )	( )	( )
Therapy targeting emotion regulation difficulties (e.g., panic, social or academic anxiety, or general stress management)	( )	( )	( )	( )	( )	( )
Weekly supportive therapy or counseling	( )	( )	( )	( )	( )	( )

Career counseling	( )	( )	( )	( )	( )	( )
Independent living training	( )	( )	( )	( )	( )	( )
Study skills and strategies	( )	( )	( )	( )	( )	( )
Peer mentoring	( )	( )	( )	( )	( )	( )
Frequent check-ins with support staff	( )	( )	( )	( )	( )	( )
Facilitated support groups with other students with shared disability	( )	( )	( )	( )	( )	( )
Opportunities to interact socially with other students	( )	( )	( )	( )	( )	( )

**28) Please rate the following services from 1 to 5 based on how helpful you think they would be for your son/daughter to receive in a college/university setting.\***

	1 (not helpful)	2 (slightly helpful)	3 (moderately helpful)	4 (very helpful)	5 (extremely helpful)
Transition services (to help with the transition to postsecondary education)	( )	( )	( )	( )	( )
Academic tutoring	( )	( )	( )	( )	( )

Speech/language services and therapies	( )	( )	( )	( )	( )
Assistive technologies	( )	( )	( )	( )	( )
Social interaction training (e.g., how to make and keep friends)	( )	( )	( )	( )	( )
Therapy targeting emotion regulation difficulties (e.g., panic, social or academic anxiety, or general stress management)	( )	( )	( )	( )	( )
Weekly supportive therapy or counseling	( )	( )	( )	( )	( )
Career counseling	( )	( )	( )	( )	( )
Independent living training	( )	( )	( )	( )	( )
Study skills and strategies	( )	( )	( )	( )	( )
Peer mentoring	( )	( )	( )	( )	( )
Frequent check-ins with support staff	( )	( )	( )	( )	( )
Facilitated support groups with other students with shared disability	( )	( )	( )	( )	( )
Opportunities to interact socially with other	( )	( )	( )	( )	( )

students					
Modified living arrangements (e.g., single room)	( )	( )	( )	( )	( )

**29) Please describe any other services you think would be helpful for your son/daughter attending a postsecondary educational institution.**

\_\_\_\_\_

**30) Please name the top two supports or services you think would help your son/daughter to succeed in his/her postsecondary educational institution.\***

1.: \_\_\_\_\_ 2.: \_\_\_\_\_

**31) Please select from the list below all strengths you believe your son/daughter has:\***

- Honesty
- Attention to detail
- Academic persistence
- Strong organizational skills
- Genuine interest in learning
- Curiosity
- Dedication to chosen field of study
- Little interest in activities that could distract from studies
- Resilience (i.e., the ability to recover from setbacks)
- Loyalty
- Superior intellectual skills
- Please list other strengths:: \_\_\_\_\_

**32) Please estimate your son's/daughter's intellectual ability.\***

- Above average (intellectually gifted)
- Intellectually average
- Below average (may have intellectual disability)

**33) Is your son/daughter currently medicated for ADHD?\***

- Yes
- No

**34) Instructions: Below is a collection of statements about your perceptions of your son/daughter. Using the 1-5 scale below, please indicate how much the statement applies to your son/daughter.\***

	1 Strongly Disagree	2 Disagree	3 Neutral	4 Agree	5 Strongly
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					Agree
Overall, I feel that my child is succeeding academically in their educational setting.	( )	( )	( )	( )	( )
My son/daughter knows what (s)he needs, likes, and is good at.	( )	( )	( )	( )	( )
My son/daughter can successfully live away from home.	( )	( )	( )	( )	( )
My son/daughter is utilizing services through their academic institution's disability office.	( )	( )	( )	( )	( )
My son/daughter has made friends in their current educational setting.	( )	( )	( )	( )	( )
My son/daughter keeps track of homework, appointments, and meetings in college.	( )	( )	( )	( )	( )
My son/daughter asserts him-/herself in group situations.	( )	( )	( )	( )	( )
My son/daughter advocates for their academic needs with instructors.	( )	( )	( )	( )	( )
My son/daughter advocates for their academic needs with classmates.	( )	( )	( )	( )	( )

My son/daughter advocates for their academic needs with the disability office.	( )	( )	( )	( )	( )
My son/daughter attends their educational institution's sponsored social gatherings (e.g. clubs).	( )	( )	( )	( )	( )
My son/daughter is invited by peers to social gatherings.	( )	( )	( )	( )	( )
My son/daughter initiates social gatherings with 1 friend	( )	( )	( )	( )	( )
My son/daughter initiates social gatherings with 2 friends	( )	( )	( )	( )	( )
My son/daughter initiates social gatherings with 3+ friends	( )	( )	( )	( )	( )
My son/daughter has a close relationship with a faculty or staff member who has helped facilitate academic success.	( )	( )	( )	( )	( )
My son/daughter attends 95% of his/her classes.	( )	( )	( )	( )	( )
I worry that my son/daughter will be taken advantage of.	( )	( )	( )	( )	( )
I support my son/daughter financially.	( )	( )	( )	( )	( )

I support my son/daughter socially.	( )	( )	( )	( )	( )
I support my son/daughter with tasks of daily living.	( )	( )	( )	( )	( )
My son/daughter is utilizing appropriate school-based supports.	( )	( )	( )	( )	( )
My son/daughter is utilizing appropriate community-based supports.	( )	( )	( )	( )	( )
I worry that my son/daughter will not graduate from their currently enrolled educational institution.	( )	( )	( )	( )	( )
My son/daughter is meeting his/her full potential.	( )	( )	( )	( )	( )

**35) Please answer B to this question.**

Cambridge University Behaviour and Personality Questionnaire For Children

**36) Please provide the response that best describes your son/daughter with ADHD for each of the following 50 items.**

	<b>Definitely Agree</b>	<b>Slightly Agree</b>	<b>Slightly Disagree</b>	<b>Definitely Disagree</b>
S/he prefers to do things with others rather than on her/his own.	( )	( )	( )	( )
S/he prefers to do things the same way over and over again.	( )	( )	( )	( )
If s/he tries to imagine something, s/he finds it very easy to create a picture in	( )	( )	( )	( )

her/his mind.				
S/he frequently gets so strongly absorbed in one thing that s/he loses sight of other things.	( )	( )	( )	( )
S/he often notices small sounds when others do not.	( )	( )	( )	( )
S/he usually notices house numbers or similar strings of information.	( )	( )	( )	( )
S/he has difficulty understanding rules for polite behaviour.	( )	( )	( )	( )
When s/he is reading a story, s/he can easily imagine what the characters might look like.	( )	( )	( )	( )
S/he is fascinated by dates.	( )	( )	( )	( )
In a social group, s/he can easily keep track of several different people's conversations.	( )	( )	( )	( )
S/he finds social situations easy.	( )	( )	( )	( )
S/he tends to notice details that others do not.	( )	( )	( )	( )
S/he would rather go to a library than a birthday party.	( )	( )	( )	( )
S/he finds making up stories easy.	( )	( )	( )	( )
S/he is drawn more strongly to people than to things.	( )	( )	( )	( )
S/he tends to have very strong interests,	( )	( )	( )	( )

which s/he gets upset about if s/he can't pursue.				
S/he enjoys social chit-chat.	( )	( )	( )	( )
When s/he talks, it isn't always easy for others to get a word in edgeways.	( )	( )	( )	( )
S/he is fascinated by numbers.	( )	( )	( )	( )
When s/he is reading a story, s/he finds it difficult to work out the characters' intentions or feelings.	( )	( )	( )	( )
S/he doesn't particularly enjoy fictional stories.	( )	( )	( )	( )
S/he finds it hard to make new friends.	( )	( )	( )	( )
S/he notices patterns in things all the time.	( )	( )	( )	( )
S/he would rather go to the cinema than a museum.	( )	( )	( )	( )
It does not upset him/her if his/her daily routine is disturbed.	( )	( )	( )	( )
S/he doesn't know how to keep a conversation going with her/his peers.	( )	( )	( )	( )
S/he finds it easy to "read between the lines" when someone is talking to her/him.	( )	( )	( )	( )
S/he usually concentrates more on the whole picture, rather than the small details.	( )	( )	( )	( )

S/he is not very good at remembering phone numbers.	( )	( )	( )	( )
S/he doesn't usually notice small changes in a situation, or a person's appearance.	( )	( )	( )	( )
S/he knows how to tell if someone listening to him/her is getting bored.	( )	( )	( )	( )
S/he finds it easy to go back and forth between different activities.	( )	( )	( )	( )
When s/he talk on the phone, s/he is not sure when it's her/his turn to speak.	( )	( )	( )	( )
S/he enjoys doing things spontaneously.	( )	( )	( )	( )
S/he is often the last to understand the point of a joke.	( )	( )	( )	( )
S/he finds it easy to work out what someone is thinking or feeling just by looking at their face.	( )	( )	( )	( )
If there is an interruption, s/he can switch back to what s/he was doing very quickly.	( )	( )	( )	( )
S/he is good at social chit-chat.	( )	( )	( )	( )
People often tell her/him that s/he keeps going on and on about the same thing.	( )	( )	( )	( )
When s/he was in preschool, s/he used to enjoy playing games involving pretending with other children.	( )	( )	( )	( )
S/he likes to collect information about	( )	( )	( )	( )

categories of things (e.g. types of cars, types of birds, types of trains, types of plants, etc.).				
S/he finds it difficult to imagine what it would be like to be someone else.	( )	( )	( )	( )
S/he likes to plan any activities s/he participates in carefully.	( )	( )	( )	( )
S/he enjoys social occasions.	( )	( )	( )	( )
S/he finds it difficult to work out people's intentions.	( )	( )	( )	( )
New situations make him/her anxious.	( )	( )	( )	( )
S/he enjoys meeting new people.	( )	( )	( )	( )
S/he is good at taking care not to hurt other people's feelings.	( )	( )	( )	( )
S/he is not very good at remembering people's date of birth.	( )	( )	( )	( )
S/he finds it very to easy to play games with children that involve pretending.	( )	( )	( )	( )

**37) Please indicate the number next to each item that best describes your son/daughter's behavior during the PAST 6 MONTHS.**

	<b>1 (Never)</b>	<b>2 (Sometimes)</b>	<b>3 (Often)</b>	<b>4 (Very Often)</b>
My son/daughter puts things off until the last minute.	( )	( )	( )	( )

My son/daughter has difficulty remembering things that he/she needs to do.	( )	( )	( )	( )
My son/daughter has trouble preparing things in advance.	( )	( )	( )	( )
My son/daughter has trouble explaining the order of tasks that need to get done.	( )	( )	( )	( )
My son/daughter has difficulty problem solving “on the spot”.	( )	( )	( )	( )
My son/daughter is impulsive.	( )	( )	( )	( )
My son/daughter often acts before thinking.	( )	( )	( )	( )
My son/daughter requires frequent supervision from others to get tasks done.	( )	( )	( )	( )
My son/daughter has difficulty inhibiting his/her responses to external events.	( )	( )	( )	( )
My son/daughter has trouble learning new or complex tasks compared to his/her peers.	( )	( )	( )	( )

**38) The questions below ask about your child's feelings in detail and especially how often your child has been bothered by a list of symptoms during the past 7 days. Please try to answer every question, even if you're not exactly sure or if you've not seen the particular behavior. For example, if your son/daughter does not live at home presently, base your answers on how you think s/he would behave or respond.\***

In the past SEVEN (7) DAYS, my child said that he/she...

	<b>1 (Never)</b>	<b>2 (Almost Never)</b>	<b>3 (Sometimes)</b>	<b>4 (Often)</b>	<b>5 (Almost Always)</b>
Felt like something awful might happen.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Felt nervous.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Felt scared.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Felt worried.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Worried about what could happen to him/her.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Worried when he/she went to bed at night.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Got scared really easy.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Was afraid of going to school.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Worried when he/she was at home.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Worried when he/she was away from home.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

---

**Please answer the following questions about yourself**

**39) Your gender:\***

- Male
- Female
- Other (e.g., transgender)

**40) Your age:\***

- 20 to 30 years old
- 31 to 40 years old
- 41 to 50 years old
- 51 to 60 years old
- 61 to 70 years old
- 71 to 80 years old
- Over 80 years old

**41) Your annual household income:\***

- Less than \$25,000
- \$25,000 to \$49,999
- \$50,000 to \$99,999
- \$100,000 or more

**42) Are you currently employed outside of the home?\***

- Yes
- No

**43) What state do you currently live in?\***

**44) Please indicate your ethnicity:\***

- Hispanic or Latino
- Not Hispanic or Latino
- Prefer not to indicate

**45) Please indicate your race from one or more of the following:\***

- American Indian or Alaska Native
- Asian
- Black or African American
- Native Hawaiian or Other Pacific Islander
- White
- Other - Please specify:: \_\_\_\_\_
- Prefer not to indicate

**46) Your highest level of schooling completed:\***

- Middle school
- High school (diploma or GED)
- Some college/technical school
- Bachelor's/4-year college degree
- Graduate school (Master's degree or above)

**47) How many children (include biological, adopted, step-, or foster) do you have?\***

- 1
- 2
- 3
- 4

- ( ) 5
- ( ) 6 or more

Thank you for completing this survey!

Following is a list of resources that you may be interested in.

<http://www.chadd.org/>  
[http://www.abct.org/Information/?m=mInformation&fa=fs\\_ADHD](http://www.abct.org/Information/?m=mInformation&fa=fs_ADHD)  
<http://www.nimh.nih.gov/health/topics/attention-deficit-hyperactivity-disorder-adhd/index.shtml>

**If you would like to receive a \$5 Amazon gift card as appreciation for completing this online survey, please assemble the following link in a new window (put the 2 components together to make the URL). We do this to prevent robots/technology from spamming the survey.**

**first component of link:** <https://www.survey>

**second component of link:** [gizmo.com/s3/1861597/Thesis-Gift-Card](https://gizmo.com/s3/1861597/Thesis-Gift-Card)

**Note:** As a shortcut, you can highlight each component individually and use *Ctrl+C* to copy and *Ctrl+V* to paste onto the new window one at a time.

Should you run into any difficulty with accessing the gift card after completing the survey, please e-mail us at [relias@vt.edu](mailto:relias@vt.edu) or call at (540) 231-2024 and we will have someone assist you.

*You will be asked only for your email address to receive the gift card.*

## Appendix C. Promis Health Organization License Agreement



**PROMIS  
HEALTH  
ORGANIZATION**

823 Monticello Place | Evanston, IL USA 60201

November 18, 2014

Rebecca Elias  
Virginia Tech Psychology Department  
109 Williams Hall (0436)  
Blacksburg, VA 24060

### LICENSE AGREEMENT

This License Agreement (this "Agreement") between the **Virginia Tech Psychology Department** ("Licensee") and The PROMIS Health Organization ("PHO") is entered into as of the date first written above (the "Effective Date"). PHO and Licensee hereby agree as follows:

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10. **Assignment.** Licensee may not assign its rights or obligations hereunder without the prior written consent of PHO, and any purported assignment shall be null and void and constitute a breach of this Agreement.

11. **Notification.** Any notification required or permitted to be given by either party to the other party pursuant to this Agreement will be in writing and will be delivered or mailed by first class mail (postage prepaid) or by overnight express addressed to the attention of the authorized representatives of such parties as follows (or such other address as either party may identify in a written notice provided in accordance with this Section): (a) if to Licensee, to the address set forth on Exhibit A; and (b) if to PHO, PROMIS Health Organization, 823 Monticello Pl, Evanston, IL 60201.

12. **Governing Law and Choice of Forum.** This Agreement shall be governed in accordance with the laws of the State of Illinois, United States of America, without regard to any provision that would result in the application of the laws of any other jurisdiction. The parties hereby irrevocably consent to the exclusive jurisdiction of, and venue in, any federal or state court of competent jurisdiction located in Cook County, Illinois for the purposes of adjudicating any matter arising from or in connection with this Agreement.

**EXHIBIT A  
TO  
LICENSE AGREEMENT**

<b>Materials Requested</b>	DSM Level 2- Anxiety-Parent measure
<b>Licensed Purpose</b> (i.e., how and where will it be used?)	Used as part of a national online survey assessing the needs, challenges, and strengths of college students with ADHD from a parent's perspective. Virginia Tech IRB approved: (# 14-181).
<b>Licensed Publication</b> (i.e., what is the larger work that will include the Materials?)	The data collected as part of this study will be used in scientific manuscripts and publications.
<b>Licensed Affiliates</b>	N/A
<b>Licensing Fee</b>	Not Applicable
<b>Royalties</b>	Not Applicable
<b>Licensee Notification Address</b>	Attn: Rebecca Elias, Virginia Tech Psychology Department, 109 Williams Hall (0436), Blacksburg, VA 24060

Appendix D.

**General Instructions**

The online survey consists of 2 qualitative open-ended questions. All standard questions should be coded unless the survey respondent did not give an answer, or gave “I don’t know” as a response; these items should be left blank.

<b>Reasoning</b>		<b>Definition</b>	<b>Example</b>
<b>Developing Competence</b>	Intellectual Competence	<ul style="list-style-type: none"> <li>• Intellectual skills</li> </ul>	“you’ve got to be paying attention to the class and taking notes”
	Interpersonal Competence	<ul style="list-style-type: none"> <li>• listening, cooperating, and communicating effectively</li> </ul>	“They have trouble chatting-small talk”
	Physical and manual competence	<ul style="list-style-type: none"> <li>• athletic and artistic achievement</li> </ul>	“People want to come to Virginia Tech because their student is good with computers” “I would always draw random things and people would find them interesting”
<b>Managing Emotions</b>	Anxiety	<ul style="list-style-type: none"> <li>• Feeling worry and/or nervousness</li> <li>• Uneasiness</li> </ul>	“We see a lot of anxiety”
	Persistence	<ul style="list-style-type: none"> <li>• Dedication and continuation in spite of difficulty</li> </ul>	“If there’s something you want to do, do it. Don’t let anything stop you.” “High level of commitment to for a lot of...seriousness of academics. They take learning seriously generally.”
	Frustration	<ul style="list-style-type: none"> <li>• Feelings of anger and annoyance</li> </ul>	“You’re overworked and you’re stressed out” “I was always so stressed and I’d shut down by the end of the day”
	Depression	<ul style="list-style-type: none"> <li>• Feeling down, inadequate, and/or guilty</li> <li>• Causes impairment</li> </ul>	“I was having a lot of issues and I was having trouble um like having regular sleep and things”
	Overwhelmed	<ul style="list-style-type: none"> <li>• Difficulty adapting to</li> </ul>	“you want to do everything, and

		<p>given circumstances</p> <ul style="list-style-type: none"> <li>• Feeling ill-equipped</li> </ul>	then you're overworked and you're stressed out"
	Inattention	<ul style="list-style-type: none"> <li>• Lack of concentration</li> <li>• Difficulty maintaining attention on one task</li> </ul>	"he is unable to focus and sit still"
Moving through Autonomy Toward Interdependence	Emotional Independence	<ul style="list-style-type: none"> <li>• Separation from parents</li> <li>• Seeking a support system</li> </ul>	<p>"I like the freedom, community, and independence"</p> <p>"towards the end of that school year I got used to being by myself"</p> <p>"They are depending on parents to tell them what to do at every turn"</p>
	Instrumental Independence	<ul style="list-style-type: none"> <li>• Organize activities</li> <li>• Solve Problems</li> <li>• Time management</li> </ul>	<p>"I was having trouble...keeping everything organized"</p> <p>"I wish I knew how to manage my time better" "everything was in one stack of papers"</p>
	Motivation	<ul style="list-style-type: none"> <li>• The desire to engage in a task</li> </ul>	"They don't give up easily...there is an insistence...like "I'm going to do it"
	Responsibility	<ul style="list-style-type: none"> <li>• Being accountable</li> </ul>	<p>"They have the counselor to hold me accountable so I have to do stuff"</p> <p>"You don't have anybody there reminding you to pay bills or whatever."</p>
Developing Mature Interpersonal Relationships	Tolerance of differences	<ul style="list-style-type: none"> <li>• Respecting differences in friends/colleagues/authority figures (can be presence or absence)</li> </ul>	<p>"Don't assume that a student that has a diagnosis of something is the same as your last student because we're different people"</p> <p>"get to know the person individually...everyone is different"</p>

	Capacity for intimacy	<ul style="list-style-type: none"> <li>• Long-lasting relationships (friend or romantic) that endure through crises, distance, and separation.</li> <li>• Ability to form friendships</li> </ul>	“We’ve had students come in and talk about being lonely...I want to have a boyfriend or girlfriend...I don’t know how to connect with people”
Establishing Identity	Self-concept	<ul style="list-style-type: none"> <li>• Levels of self-esteem</li> <li>• Making an attempt at self-discovery or identity formation</li> <li>• Exploring your interests, beliefs, or culture</li> </ul>	“I feel like there’s no sense in trying because what I’m trying to say is probably boring” “I found that very beneficial, you know, taking a couple years or whatever to just kind of learn about yourself”
	Stability	<ul style="list-style-type: none"> <li>• Maintaining stability among competing influences (work, school, friendships, etc.)</li> </ul>	“It’s like a big balancing act” “you have to be multiple places at different parts of campus at different times”
Developing Purpose	Vocational Plans and Aspirations	<ul style="list-style-type: none"> <li>• Plans for future employment</li> </ul>	“There’s a difference between you having a job and getting fired if you don’t make that deadline. So I’m wondering what might be offered to these kids on that other side”
	Personal Interests	<ul style="list-style-type: none"> <li>• To be excited about something</li> </ul>	“I would always draw random things...I have a passion for creativity” “I wanted to join all the clubs, you want to do everything”
	Interpersonal and Family Commitments	<ul style="list-style-type: none"> <li>• Levels of commitment to family or other relationships</li> </ul>	“They...start to realize that I do have some freedom and I don’t have to talk to my parents if I don’t want to.”
Developing Integrity	Values	<ul style="list-style-type: none"> <li>• Rules, judgments, and beliefs based on reason, faith, or intuition</li> </ul>	“And then they really challenge their professors on a lot of things and say that’s not true...”  “they want to understand... the rules and the process, so that’s a good thing. They tend to tend to really want to understand.”

Other	Keeping up with the pace	<ul style="list-style-type: none"> <li>Recognizing and managing difficulties with increasing workload</li> <li>Keeping up with other students</li> </ul>	<p>“I also have a hard time keeping up with the things I am supposed to be doing.”</p> <p>“I need time to think and they just want to do now, now, now”</p>
	Taking risks	<ul style="list-style-type: none"> <li>Leaving their comfort zone</li> <li>Attempting a task without being sure of what the results will be</li> </ul>	<p>“They see ‘Wow I really can do this.’ and it wasn’t comfortable going into it but overcame it.”</p> <p>“The only way they can do [learn] socialization is by being social”</p>
	Physical Space	<ul style="list-style-type: none"> <li>Difficulty or acceptance of more than one person in a given environment (physical in nature)</li> </ul>	<p>“I struggle with overcrowding”</p>
	Substance Abuse	<ul style="list-style-type: none"> <li>Using illegal substances such as marijuana, alcohol, etc.</li> </ul>	<p>“we noticed a significant problem with partying and alcohol”</p>
	Prescription Medication	<ul style="list-style-type: none"> <li>Using medication such as mood stabilizers or stimulants</li> </ul>	<p>“He refuses ADD Rx”</p>
	Decision Making	<ul style="list-style-type: none"> <li>Commitment or lack of commitment to a personal choice</li> </ul>	<p>“I’ve also had a hard time of being decisive”</p>
	Transportation	<ul style="list-style-type: none"> <li>Getting to different locales</li> </ul>	<p>“She just learned to drive. A whole world is opening up”</p> <p>“He doesn’t know how to use public transportation”</p>
	Non-intentional forgetting	<ul style="list-style-type: none"> <li>Forgetting, losing, or misplacing physical items or ideas</li> </ul>	<p>“He forgets assignments”</p>