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Autism goes to College: Understanding the Needs of a Student Population on the Rise

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Abstract

Understanding the needs of adolescents and emerging adults with Autism Spectrum Disorder (ASD) with respect to transition to postsecondary education is critical to development of user-informed transition programming. Parents of adolescents and emerging adults with ASD ($n = 52$) and ADHD ($n = 47$) completed an online survey. Social interaction training and independent living training were services frequently requested by parents in the ASD group. Additionally, parents of postsecondary students with ASD endorsed distinct challenges with self-advocacy, managing emotions, and managing personal/adaptive skills relative to postsecondary students with ADHD. The profile of parent-reported difficulties and needed services compared to transition to postsecondary education for students with ASD is distinguishable from that for ADHD, suggesting individualized transition planning and in-college supports.

Keywords

autism; emerging adult; postsecondary; transition

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 and responsibility (Arnett, 2000). This is also the age range during which most individuals transition from secondary school to either postsecondary education or employment. As critical as this developmental period is, it has been understudied in Autism Spectrum Disorder (ASD). Students in postsecondary education face increased social, emotional, and organizational demands associated with the period of emerging adulthood (Arnett, 2000); these demands are often amplified for students with neurodevelopmental disorders such as ASD (Wenzel & Brown, 2014; White et al., 2016). ASD and Attention-Deficit/Hyperactivity Disorder (ADHD) are neurodevelopmental disorders which are typically identified during childhood yet persist into adulthood

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Informed consent: Informed consent was obtained from all individual participants included in the study.

(American Psychiatric Association, 2013). In addition to age-normative demands faced by all individuals matriculating into college, students with neurodevelopmental disabilities, such as ASD and ADHD, must also learn how to self-advocate for needed services or accommodations during this transition.

Emerging adults with ADHD have overlapping phenotypic characteristics with emerging adults with ASD and high co-occurrence between the two disorders (American Psychiatric Association, 2013; Levy 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, common across both disorders, are hypothesized as one common facet contributing to poor outcomes (Fleming & McMahon, 2012; Gobbo & Shmulsky, 2013; Hewitt, 2011). Executive functioning is loosely defined as the ability to engage in goal-directed behavior (Barkley, 1997; Roberts & Pennington, 1996). Despite impairment, gaps in structured psychosocial service provision during the transition to adulthood exist, for students with ADHD and ASD alike (Cadman et al., 2012; Hall et al., 2013; Swift et al., 2013). As a result, parents often aid their grown children in the postsecondary environment to ensure success (Cadman et al., 2012).

The current investigation sought to inform our understanding of the transition-related needs of emerging adults with ASD, from a parent stakeholder perspective. By integrating a comparator group, parents of emerging adults with ADHD, the specificity (i.e., not just related to emerging adulthood or neurodevelopmental disorders more broadly) of the challenges and needs of adolescents and emerging adults with ASD could be examined. For the present study, parents were chosen as the primary informant group because they are pivotal in assisting their offspring with the identity development, emotional, and educational/vocational transitions associated with developmental maturation.

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 many students do not reveal their diagnoses to educational support staff (Wenzel & Brown, 2014), and some students are not diagnosed until during or after college (White et al., 2011). Despite structured transition plans crafted during the high school years, support systems are often not readily available. This problem is often compounded by a loss of additional services provided outside the school, such as psychotherapy (Levy & Perry, 2011; Shattuck, et al., 2012). Postsecondary students with disabilities are protected by the Americans with Disabilities Act (ADA), a system reliant on self-advocacy and demonstration of need. Academic services are typically limited to appropriate accommodations which do not alter the core curriculum (Wenzel & Brown, 2014). Additionally, many of the services implemented during the K-12 Individualized Education Plan (IEP) are not covered under ADA auspices (Wenzel & Brown, 2014). For young people with ASD, the first two years after high school completion are characterized by low rates of paid employment and continuation of schooling, relative to individuals with a speech and language impairment, learning disability, or intellectual disability (Shattuck et al., 2012). Although postsecondary success has been reported to be associated with utilization of offered supports in students with ASD (VanBergeijk, Klin, & Volkmar, 2008),

in general students with ASD tend to experience scholastic underachievement despite being well-prepared intellectually and academically, (Kapp, Gantman, & Laugeson, 2011). Core ASD features (e.g., difficulty with changes in longstanding routines or environment), deficient daily living skills, and limitations in executive functioning abilities may hamper success in postsecondary education (Hewitt, 2011; Test, Smith, & Carter, 2014; VanBergeijk et al., 2008). However, these features have not been examined from a parental perspective.

Between 2 and 8% of college students have an ADHD diagnosis (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). Compared to students without ADHD, those with ADHD often have lower grade point averages, take longer to complete their academic degrees, and have lower graduation rates (Barkley et al., 2008; Schwanz, Palm, & Brallier, 2007). Similar to ASD, emerging adults with ADHD display deficits in social skills and lower quality of life when compared to typically developing students (Friedman et al., 2003; Shaw-Zirt, Popali-Lehane, Chaplin, & Bergman, 2005). Additionally, students with ADHD exhibit increased risk for patterns of substance abuse (Rooney, Chronis-Tuscano, & Yoon, 2012).

A pilot, qualitative study on ADHD in college students identified three primary themes which may contribute to success: 1) gaining insight about ADHD, 2) managing life (i.e., related to ADHD symptomatology and addictive behaviors), and 3) utilizing sources of support (Meaux, Green, & Broussard, 2009). Parents play an important role during this developmental phase in many ways; they often provide financial assistance, help ensure college completion, and assist in the penultimate goal of independence as an adult. Further, parents of individuals with ASD identify a need and desire to be involved in transitions to adulthood (Stoner, Angell, House, & Bock, 2007). In exploring the needs of students with ASD during this period in particular, utilizing parents as informants may be ideal, as research has shown that even higher functioning individuals with ASD often over-rate their personal social functioning when compared to parent-report (Lerner, Calhoun, Mikami, & De Los Reyes, 2012).

Parent involvement in the transition from secondary to postsecondary education is one factor involved in favorable later outcomes in the educational setting (Eckes & Ochoa, 2005). Morrison et al. (2009) assessed, via a single focus group, four parents of high school students with ASD in the same geographic region. Results suggested that parents perceived challenges with self-advocacy and a desire for appropriate supports and accommodations at the university level. The present study sought to expand this preliminary work by targeting a larger and more geographically diverse participant group. Additionally, the present study looked at three informant groups (parents of high school students, parents of postsecondary students, and parents of emerging adults not currently enrolled in formal education) to assess if perceived needs vary as a function of group identification.

The goal of this study was to determine the challenges and needs encountered by students with ASD related to postsecondary education. Specifically, we sought to identify the parent-identified challenges and support needs of students with ASD who are either attending a

postsecondary institution or are postsecondary-bound. Based on a preliminary study (Duke et al., 2013), it was hypothesized that parents would identify prominent challenges related to time-management, self-determination, social isolation, and self-regulation. To determine the specificity of challenges, we employed a comparison group of parents of emerging adults with ADHD.

Method

Procedure

In an effort to ascertain a diverse sample, the study used an anonymous online survey distributed nationwide. The survey was created in SurveyGizmo® and data collection occurred over a 10-month period. After receiving the online survey link, participants consented to study participation, per the institution's approved IRB protocol. Next, participants answered a series of demographic questions and 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.

Participants

Participants were men and women who identified as parents of individuals with ASD or 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 are not currently enrolled in high school or college. 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, must begin (The Individuals with Disabilities Act [IDEA], 2004). Parents of individuals with ASD were not excluded if their child also had a comorbid diagnosis of ADHD. The upper age limit of 25 was selected because ages 18 to 25 encapsulates emerging adulthood (Arnett, 2000), and it is often in this span that individuals transition into postsecondary education if they have deemed it a desired goal.

Flyers, email distribution, and online resources were used to recruit participants locally and nationally. Specifically, the study was advertised as a survey for parents of individuals with ASD related to the transition out of high school and into higher education. Local advertising occurred in Southwest Virginia (in the community as well as 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 [omitted for review] Department of Psychology, and ASD registries were also targeted. At the national level, ASD and ADHD-specific online blogs and websites (e.g., sites focused on ASD, ADHD, parenting) were used. Electronic announcements advertising the survey were sent out to postsecondary institutions in all 50 states. Additionally, individual counselors and psychological services centers were contacted in all 50 states.

One hundred and forty-three people began the survey. Participants who only partially completed the survey ($n = 27$), had a son/daughter who did not meet inclusion criteria (i.e., no ASD or ADHD diagnosis, outside of the 16–25 year age range, $n = 14$), or resided outside of the United States as determined by their IP address ($n = 3$) were excluded, yielding a final sample size of 99 (ASD, $n = 52$; ADHD, $n = 47$). Participation was limited to individuals within the United States, as all of the recruitment efforts occurred nationally. Parents self-identified as current or former legal guardians. Fifty-two parents of an individual with ASD and 47 parents of an individual with ADHD completed the online survey (see Figure 1 for a visual of included participants). All participants received a modest honorarium in the form of a gift card.

Descriptive statistics were computed for all demographic variables of parent respondents and demographic variables of their identified son or daughter (Table 1). Parent-reported demographic variables for their offspring with ASD or ADHD consisted of chronological age, age of diagnosis, sex, postsecondary field of study, and whether or not they were involved in their transition IEP (Table 1). The chronological age of the emerging adult identified with ASD or ADHD ranged from 16–25 and the difference in age between the ASD and ADHD 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 and ADHD groups, $t(97) = 3.104$, $p = 0.003$, such that on average ASD was diagnosed approximately 3 years earlier than ADHD. This is consistent with epidemiological data suggesting that the mean age of diagnosis of individuals with ASD is earlier than individuals with ADHD (American Psychiatric Association, 2013).

Evaluation Measures

Online Survey—The survey content was developed based on prior pilot studies (e.g., Duke, Conner, Kreiser, Hudson, & White, 2013), theory (e.g., Wehmeyer, Shogren, Zager, Smith, & Simpson, 2010), contributions from experts in the field, and a preliminary pilot study. The pilot study was comprised of interviews conducted with four mothers of emerging adults with ASD, in order to identify prominent or probable themes. Forced choice integrated with free response modalities was used to increase richness of the dataset, as simultaneous use of qualitative and quantitative methods can provide a complementary mixed-methods perspective (Palinkas, 2014; Yardley & Bishop, 2007). The survey took an average of 34 minutes (*range: 5–170 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. Survey respondents answered a maximum of 47 questions. This study specifically examined parent-identified educational challenges and areas of service need for their son/daughter with ASD or ADHD. Specifically, parents quantitatively 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 (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) based on what they perceived to be challenging for their emerging adult with a disability in the postsecondary setting. Additionally, parents were quantitatively 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 (1 = not helpful, 2 = slightly helpful, 3 = moderately helpful, 4 = very helpful, 5 = extremely helpful) based on what they perceived to be helpful services for their child with a disability in the postsecondary setting. Two open-ended questions served as the primary items for qualitative data analysis. These included, "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 "Please describe any other services you think would be helpful for your son/daughter attending a postsecondary educational institution."

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 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 (Auyeung et al., 2007). The mean total score for the ASD group ($M = 92.08$, $SD = 16.16$) exceeded the clinical cutoff and the mean total score for the ADHD group ($M = 64.77$, $SD = 17.75$) 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.

Executive Functioning Measure—Because a brief measure of executive function suitable for online administration was not available, a brief, study-specific measure was created. The measure was based on Barkley's theory of executive function (Barkley, 1997; Barkley, 2012) and piloted internally prior to the study. The executive function measure was a 10-item Likert measure (1=never, 2=sometimes, 3=often, 4=very often) designed to assess executive dysfunction in over the past 6 months. Sample items include, "My son/daughter often acts before thinking" and "My son/daughter has difficulty remembering things that he/she needs to do". Internal consistency for this sample was good, $\alpha = 0.811$ for the total sample, $\alpha = 0.866$ for the ADHD group, and $\alpha = 0.758$ for the ASD group.

Analyses

After excluding cases not meeting inclusion criteria, 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, and 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 based on preliminary piloting of the survey, which was a maximum of 47 questions. Seven survey participants finished the survey in less than 2 minutes and were removed from final analyses. A minimum completion time of was established to eliminate responses generated by non-human respondents (i.e., robots). 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 analyses. Sample sizes were fairly equitable across groups. Skewness, kurtosis, and normality were assessed and within acceptable limits for all measures.

Since formal diagnoses cannot be confirmed via online survey methodology, the AQ and executive functioning profile were used to characterize the sample based on symptomatology. In order to distinguish shared versus unique challenges and needed services to those with ASD and ADHD, we first identified the top challenges and needed services of individuals with ASD and ADHD (i.e., overall means). Next, group differences were examined to determine diagnostic specificity of the identified challenges. 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 response items. Statistical significance of the Wilk’s Lambda for the omnibus MANOVA was set at $p < 0.01$, given the small sample size and pilot nature of this study. The Bonferroni correction method was considered to control for the familywise error rate with subsequent pair comparisons. However, there is a lack of consensus on when Bonferroni procedures should be used (Perneger, 1998) and many argue that the inflated Type II error risk does not justify its use in preliminary studies (Gelman, Hill, & Yajima; Nakagawa, 2004). In order to facilitate a more fine-grained examination of the specific challenges at the postsecondary level, we also examined group differences between parents of postsecondary students with ASD ($n = 22$) and postsecondary students with ADHD ($n = 25$).

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 and informed by ASD-specific focus groups (White et al., 2016) 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 A) was then applied to the full set of free response questions. Two independent coders who were unaware of group (ASD, ADHD) coded all qualitative text responses. Coders were trained by the lead author using a subset of

the text responses. Disagreements were resolved through discussion-based consensus. After fully trained, 20% of the qualitative text responses were coded. This yielded a reliability Kappa of .77 (i.e., substantial agreement; Landis & Koch, 1977).

Results

Characterization of Sample

The ASD ($M = 92.08$, $SD = 16.16$) and ADHD ($M = 64.77$, $SD = 17.75$) groups significantly differed on symptoms of ASD per the AQ, $t(97) = -8.015$, $p = 0.001$. However, the ASD ($M = 25.96$, $SD = 5.02$) and ADHD ($M = 26.23$, $SD = 6.67$) groups did not significantly differ on the executive functioning profile, $t = 0.229$, $p = 0.820$. Bivariate correlations among the AQ and executive functioning profile did not yield significance indicating that the constructs assessed by each measure did not significantly overlap ($r = 0.162$). Both groups had high rates of service utilization across the lifespan. Of note, 48.1% of the ASD sample and 48.9% of the ADHD sample had received psychotropic medication as part of their service regimen. The majority (86.5%) of individuals with ASD had engaged in social skill intervention, with most commencing this service between the ages of 5 to 10 years (42.3%). Likewise, academic accommodations were provided to 90.4% of students with ASD and 78.7% of students with ADHD at some point during their schooling. Just over half of individuals with ASD received independent living training at some point during their development with approximately equal distribution before the age of 15 (25%) and over the age of 15 (26.9%). Individuals with ADHD engaged in less social skill intervention $t(97) = 5.870$, $p < 0.001$ and independent living skill training $t(97) = 5.332$, $p < 0.001$.

Parent Identified Challenges and Needed Supports

Qualitative Responses—Seventy-three individuals responded to at least one open-ended question. For each of the qualitative question (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 (Sofaer, 1999). Due to significant missing data on the qualitative items resulting in uneven subgroups, the study compared parent perspectives of individuals with ASD to those of ADHD, regardless of educational status. Parents of individuals with ASD cited social difficulties as principal difficulties for their son or daughter. Specifically, Interpersonal Competence was the most prominent 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 rated as the second highest area of difficulty for transition or postsecondary aged individuals with ASD. Capacity for Intimacy was defined as the ability and desire 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.

Parents of individuals with ASD reported Instrumental Independence as the domain which necessitated the most services, closely followed by Interpersonal Competence. 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—Table 2 stratifies endorsed challenges for students with ASD and ADHD, in addition to group differences. Social interaction was cited largely as a top difficulty for parents of individuals with ASD across educational strata. Parents of emerging adults with ADHD as a whole cited attention as top identified challenge.

A two-way MANOVA¹ 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' $\Lambda = 0.561$. Table 2 details the group differences among parents of individuals with ASD and ADHD. Parents of individuals with ASD reported greater struggle with social interactions [$F(1, 97) = 23.99, p = 0.001$], social support [$F(1, 97) = 21.45, p = 0.001$], 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 [$F(1, 97) = 15.99, p = 0.001$] relative to parents of emerging adults with ASD. Similar to the diagnostic comparison, parents of postsecondary students with ASD reported difficulties with social interactions [$t(44) = 4.112, p = 0.001$], social support [$t(44) = 3.755, p = 0.001$], and living arrangements [$t(44) = 3.384, p = 0.002$] compared to parents of postsecondary students with ADHD. Parents of postsecondary students with ASD also reported greater difficulty with self-advocacy [$t(44) = 2.908, p = 0.006$], managing intense emotions [$t(44) = 3.158, p = 0.003$], and managing personal/adaptive skills [$t(44) = 3.371, p = 0.002$] when compared to students with ADHD.

Endorsed requested services in addition to group differences are detailed in Table 3. Parents in the ASD group cited opportunities to interact socially with other student, transition services, and independent living training as primary needed services in the postsecondary domain. Parents of students with ADHD indicated academic tutoring as a primary needed service in the postsecondary placement.

A two-way MANOVA¹ 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' $\Lambda = 0.791$. The main effect for educational placement was not significant, $F(30, 158) = 1.118, p = 0.321$; Wilks' $\Lambda = 0.680$. There was a

¹Non-parametric tests revealed no relationship between the type of school attended and the student's diagnostic group.

significant main effect for diagnosis, $F(15, 79) = 4.023, p = 0.001$; Wilks' $\Lambda = 0.567$. 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 [$F(1, 97) = 22.10, p = 0.001$], and modified living arrangements [$F(1, 97) = 15.48, p = 0.001$] more so 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 more helpful/desired than parents in the ASD group. These same services emerged between group comparisons of postsecondary students only. Specifically, parents of postsecondary students with ASD reported requested the same supports of speech/language services and therapies [$t(44) = 2.843, p = 0.007$], social interaction training [$t(44) = 3.755, p = 0.001$], independent living training [$t(44) = 4.423, p = 0.001$], and modified living arrangements [$t(44) = 2.809, p = 0.007$], compared to parents of postsecondary students with ADHD.

Discussion

This study investigated challenges and needed supports among emerging adults with ASD, from parents' perspectives. 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 hallmark social disability of ASD (American Psychiatric Association, 2013) and the adult outcomes of those with ASD, indicating that individuals are not fully independent but instead largely reliant on others for support (Howlin, Goode, Hutton, & Rutter, 2004). Moreover, these results are the first to suggest that parents identify social difficulties into adulthood that are impairing to postsecondary success. 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 young adult sample. These challenges differed significantly from those faced by emerging adults with ADHD. Specifically, parents report that emerging adults with ADHD struggle primarily with time management and attention. This finding is largely consistent with the literature (Cheung et al., 2015) and with diagnostic criteria for ADHD (American Psychiatric Association, 2013). However, the lack of parent-reported difficulties with time management and attention among parents of emerging adults with ASD is noteworthy, considering the high level of comorbidity of ADHD among people with ASD (Levy et al., 2010) and the almost identical presentation on the executive functioning measure in this study. This pattern of results suggests that social impairment and independent living skill development are more pressing needs for college students with ASD, regardless of potentially co-occurring ADHD-related difficulties.

When examining results only at the postsecondary level, parents of college students with ASD endorsed unique challenges relative to postsecondary students with ADHD. Specifically, the inclusion of difficulties with self-advocacy, managing intense emotions, and managing personal/adaptive skills suggest that these needs may be distinct from students with ASD who are either in high school or not currently enrolled in formal education.

Specifically, it appears that difficulties with speaking up for oneself and emotion regulation are pervasive in the postsecondary domain. As such, integrating these areas into planning prior to the transition to the postsecondary setting could prove beneficial.

Despite the fact that time management and attention were not uniformly identified as a primary challenge area in the ASD group, qualitative results suggest that supports for executive function impairments, along with social competence training, are indeed needed. Supports for social impairments 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, and strongly suggests that interventions designed to target transitioning or postsecondary students with ASD need to encompass social skill training and opportunity.

Parents in both groups (ASD and ADHD) identified a high need for supports, both emotional and tangible in nature, for living outside of the home. These results are consistent with prior research that has identified achieving independence as a primary coming of age task that all postsecondary students integrate into their skillset and identity (Chickering and Reisser, 1993). Future research should determine if there are certain types of independent living supports that are uniquely suited to address the needs of emerging adults with ASD or ADHD.

There are several limitations to note in this study. First, the total sample was relatively small and the study was therefore not powered to detect differences among all six informant groups. Additionally, diagnosis was not confirmed in this study and it is possible that the monetary incentive prompted some participants to complete the survey even if their child did not meet the diagnostic inclusion criteria. 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 terminology, owing in part to the change from DSM-IV to DSM-5 (American Psychiatric Association, 2013), with regards to clinical diagnoses influenced the parents who responded to the online survey. However, our recruitment efforts were stringent, specifically targeting parents with previously diagnosed offspring of the target age-range (e.g., registered participants on ASD-specific listservs), as opposed to more generic online sample ascertainment tools. Although this approach may represent a strength in participant characterization, it may have yielded a parent sample that is not fully reflective of the wider, more diverse population, which limits generalizability. Our sample was primarily White and fairly affluent. Further research should implement the use of a diverse, typically developing comparison sample, as this is a relative limitation of the paper. Another potential limitation relates to the design of the study, in that all of the data came from a single source (parent-report) and modality (online survey). Lastly, construct validity of the executive functioning profile was not established.

Our finding that educational placement was not a significant predictor of either endorsed challenges or requested supports is surprising, given the legal responsibility required to support and assist those with a documented disability in high school and college versus no schooling. Although a number of variables may have contributed to this finding, we hypothesize that perhaps the high utilization of services across the lifespan, including

services external to formal schooling, may have ameliorated unique effects to a student's educational status. This is, however, speculative and further research is warranted to see if this replicates.

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 their needs related to transition. The findings presented herein may inform college disability support services as well as future transition-based structured programming aimed to address the needs of young adults with ASD in the college environment. The primary needs and challenges faced 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. In comparison to students with ADHD, these needs appear to be unique to ASD, and 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.

The quantitative and qualitative group differences among those with ASD and ADHD is noteworthy, specifically with regard to practical application. The differences among endorsed challenges and requested supports suggests that perhaps individuals with ASD have a unique profile which needs to be addressed through school-based disability personnel as well as external (non-mandated) supports. For example, social-related supports are not mandated under the auspices of ADA, suggesting that programming beyond legal mandates may be beneficial to functioning in the postsecondary domain.

It is often difficult for service providers and mental health clinicians to reach out to young adults with ASD, especially within the postsecondary educational setting, for a variety of reasons. College students are generally not actively seeking out treatments or services, nor are they usually accustomed to independently seeking out services - even when services are needed. Additionally, students with ASD in particular may not be inclined to participate in social interventions. As such, services and supports to promote college success may be most successful if they are initiated before the student transitions out of secondary school, when parents are often still involved in this process and the primary conduit between providers and students. As these families face the prospect of college and independent living, programming that addresses both core (e.g., social disability) and developmental (e.g., growing self-advocacy, functional independence) may be extremely helpful.

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Appendix A

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.

Reasoning		Definition	Example
Developing Competence	Intellectual Competence	<ul style="list-style-type: none"> Intellectual skills 	"you've got to be paying attention to the class and taking notes"
	Interpersonal Competence	<ul style="list-style-type: none"> listening, cooperating, and communicating effectively 	"They have trouble chatting-small talk"
	Physical and manual competence	<ul style="list-style-type: none"> athletic and artistic achievement 	"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"
Managing Emotions	Anxiety	<ul style="list-style-type: none"> Feeling worry and/or nervousness Uneasiness 	"We see a lot of anxiety"
	Persistence	<ul style="list-style-type: none"> Dedication and continuation in spite of difficulty 	"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"> Feelings of anger and annoyance 	"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"> Feeling down, inadequate, and/or guilty Causes impairment 	"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"> Difficulty adapting to given circumstances Feeling ill-equipped 	"you want to do everything, and then you're overworked and you're stressed out"
	Inattention	<ul style="list-style-type: none"> Lack of concentration Difficulty maintaining attention on one task 	"he is unable to focus and sit still"
Moving through Autonomy Toward Interdependence	Emotional Independence	<ul style="list-style-type: none"> Separation from parents Seeking a support system 	"I like the freedom, community, and independence" "towards the end of that school year I got used to being by myself"

Reasoning		Definition	Example
			"They are depending on parents to tell them what to do at every turn"
	Instrumental Independence	<ul style="list-style-type: none"> Organize activities Solve Problems Time management 	"I was having trouble... keeping everything organized" "I wish I knew how to manage my time better" "everything was in one stack of papers"
	Motivation	<ul style="list-style-type: none"> The desire to engage in a task 	"They don't give up easily...there is an insistence...like "I'm going to do it"
	Responsibility	<ul style="list-style-type: none"> Being accountable 	"They have the counselor to hold me accountable so I have to do stuff" "You don't have anybody there reminding you to pay bills or whatever."
Developing Mature Interpersonal Relationships	Tolerance of differences	<ul style="list-style-type: none"> Respecting differences in friends/ colleagues/ authority figures (can be presence or absence) 	"Don't assume that a student that has a diagnosis of something is the same as your last student because we're different people" "get to know the person individually...everyone is different"
	Capacity for intimacy	<ul style="list-style-type: none"> Long-lasting relationships (friend or romantic) that endure through crises, distance, and separation. Ability to form friendships 	"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"> Levels of self-esteem Making an attempt at self-discovery or identity formation Exploring your interests, beliefs, or culture 	"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"> Maintaining stability among competing influences (work, school, friendships, etc.) 	"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"> Plans for future employment 	"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"

Reasoning		Definition	Example
	Personal Interests	<ul style="list-style-type: none"> To be excited about something 	"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"> Levels of commitment to family or other relationships 	"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"> Rules, judgments, and beliefs based on reason, faith, or intuition 	"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"> Recognizing and managing difficulties with increasing workload Keeping up with other students 	"I also have a hard time keeping up with the things I am supposed to be doing." "I need time to think and they just want to do now, now, now"
	Taking risks	<ul style="list-style-type: none"> Leaving their comfort zone Attempting a task without being sure of what the results will be 	"They see 'Wow I really can do this.' and it wasn't comfortable going into it but overcame it." "The only way they can do [learn] socialization is by being social"
	Physical Space	<ul style="list-style-type: none"> Difficulty or acceptance of more than one person in a given environment (physical in nature) 	"I struggle with overcrowding"
	Substance Abuse	<ul style="list-style-type: none"> Using illegal substances such as marijuana, alcohol, etc. 	"we noticed a significant problem with partying and alcohol"
	Prescription Medication	<ul style="list-style-type: none"> Using medication such as mood stabilizers or stimulants 	"He refuses ADD Rx"
	Decision Making	<ul style="list-style-type: none"> Commitment or lack of commitment to a personal choice 	"I've also had a hard time of being decisive"
	Transportation	<ul style="list-style-type: none"> Getting to different locales 	"She just learned to drive. A whole world is opening up"

Reasoning		Definition	Example
			"He doesn't know how to use public transportation"
	Non-intentional forgetting	<ul style="list-style-type: none"> Forgetting, losing, or misplacing physical items or ideas 	"He forgets assignments"

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Figure 1.
Participant Sample

Table 1

Demographic Characteristics of Parent Participants (n = 99).

Parent Demographics	ASD (<i>n</i> = 52)	ADHD (<i>n</i> = 47)
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	1.92	0
Pacific Islander		
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</i> , <i>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
Student Demographics	ASD (<i>n</i> = 52)	ADHD (<i>n</i> = 47)
Chronological Age (<i>M</i> , <i>SD</i>)	19.17 (2.41)	19.57 (2.79)
Age of Diagnosis (<i>M</i> , <i>SD</i>)	8.07 (5.23)	11.32 (5.16)
Males (%)	76.92	68.09
Participation in Transition IEP (%)	13.5	8.51
Postsecondary Schooling (%) ^a	(<i>n</i> = 22)	(<i>n</i> = 25)
Science	4.55	20.00
Engineering	9.09	12.00

Parent Demographics	ASD (<i>n</i> = 52)	ADHD (<i>n</i> = 47)
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

^aThis demographic refers only to students who were enrolled in postsecondary education. Participants were allowed to choose more than one option for this item: "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"

Table 2

Parent endorsed challenges for individuals with ASD or ADHD

Challenges	ASD (<i>n</i> = 52)				ADHD (<i>n</i> = 47)		<i>F</i>	<i>p</i> -Value
	Postsecondary <i>M</i> (<i>SD</i>)	High School <i>M</i> (<i>SD</i>)	No Schooling <i>M</i> (<i>SD</i>)	Postsecondary <i>M</i> (<i>SD</i>)	High School <i>M</i> (<i>SD</i>)	No Schooling <i>M</i> (<i>SD</i>)		
Self-advocacy	3.591(0.796)	3.150(0.988)	2.900(0.738)	2.917(0.776)	2.800(1.014)	2.878(1.246)	5.189	0.25
Time management	3.455(1.011)	2.950(0.999)	3.200(1.135)	3.750(1.032) ^b	3.800(1.146)	4.250(0.886)	9.360	0.003 [*]
Motivation	2.773(1.232)	3.050(1.146)	3.000(1.155)	3.000(1.216)	3.533(1.125)	3.750(0.886)	2.558	0.113
Goals	2.909(1.377)	3.150(1.182)	3.500(0.972) ^a	2.708(1.083)	3.000(1.000)	3.500(0.756)	0.610	0.437
Managing intense emotions	3.591(0.796)	2.950(1.356)	3.100(0.876)	2.750(0.989)	3.267(1.438)	3.875(1.126)	0.385	0.536
Stress with school demands	3.682(0.945)	2.900(1.119)	3.200(1.687)	3.792(0.932)	3.133(1.125)	3.875(0.641)	1.884	0.173
Conduct/behavioral Issues	2.000(0.873)	2.200(1.281)	1.900(0.994)	1.375(0.770)	2.200(1.320)	2.625(1.188)	0.875	0.352
Attention	3.227(1.066)	3.200(0.951)	3.100(1.197)	3.708(0.751)	4.000(0.756) ^b	4.500(0.756) ^b	15.986	<0.001 [*]
Managing life tasks	3.273(1.032)	3.150(1.089)	2.900(1.370)	3.541(1.062)	3.667(1.175)	4.125(0.991)	5.685	0.019
Social interactions	3.818(1.220) ^a	3.950(0.887) ^a	3.400(1.430)	2.458(1.021)	2.800(1.146)	3.000(1.512)	23.986	<0.001 [*]
Social support	3.591(1.221)	3.600(1.142)	3.400(1.430)	2.375(0.970)	2.467(1.125)	2.750(1.581)	21.452	<0.001 [*]
Managing personal/adaptive skills	3.318(1.249)	3.150(1.182)	3.100(1.197)	2.208(0.977)	2.600(1.352)	3.875(1.457)	5.576	0.020
Co-occurring psychiatric concerns	3.227(1.270)	2.650(1.309)	2.600(1.578)	2.833(1.373)	2.400(1.454)	3.125(1.553)	0.252	0.617
Living arrangements	3.227(1.270)	2.800(1.642)	3.500(1.269) ^a	2.083(1.018)	2.200(1.373)	3.500(1.512)	7.467	0.007 [*]
Closeness to family	2.409(1.054)	2.450(1.356)	2.000(0.667)	2.333(1.050)	1.733(0.884)	2.250(1.282)	0.994	0.321

Note:

^a = Top cited area of concern for individuals with ASD.^b = Top cited area of concern for individuals with ADHD.^{*} = Significance at the *p* < 0.01 level.

Table 3

Parent endorsed needed supports for individuals with ASD or ADHD

Supports	ASD (<i>n</i> = 52)			ADHD (<i>n</i> = 47)		<i>F</i>	<i>p</i> -Value
	Postsecondary <i>M</i> (<i>SD</i>)	High School <i>M</i> (<i>SD</i>)	No Schooling <i>M</i> (<i>SD</i>)	Postsecondary <i>M</i> (<i>SD</i>)	High School <i>M</i> (<i>SD</i>)	No Schooling <i>M</i> (<i>SD</i>)	
Transition services	3.818(1.220)	4.350(1.089) ^a	4.000(1.333)	3.583(1.248)	4.067(0.961)	3.625(1.060)	1.781 0.185
Academic tutoring	3.636(1.432)	3.400(1.536)	3.800(1.229)	4.333(0.868) ^b	4.333(0.900) ^b	3.875(0.991)	7.893 0.006*
Speech/Language	2.636(1.733)	2.900(1.447)	3.000(1.563)	1.417(1.139)	2.333(1.543)	1.375(0.517)	14.641 <0.001*
Assistive Technology	3.000(1.543)	2.850(1.600)	3.000(1.700)	2.042(1.488)	3.533(1.552)	2.500(1.512)	1.168 0.282
Social Interaction Training	4.091(1.269)	3.900(0.912)	4.000(1.333)	2.292(1.367)	3.067(1.792)	3.125(1.727)	22.869 <0.001*
Emotion Regulation Therapy	4.318(1.086)	3.650(1.226)	3.700(1.418)	3.583(1.381)	3.400(1.454)	3.375(1.302)	3.022 0.085
Weekly Therapy/Counseling	4.000(1.234)	3.500(1.504)	3.600(1.577)	3.333(1.373)	3.267(1.387)	3.750(1.282)	1.580 0.212
Career Counseling	3.864(0.941)	4.050(1.191)	3.900(1.287)	3.625(1.313)	4.000(1.195)	3.750(1.389)	0.551 0.460
Independent Living Training	3.773(1.307)	4.000(1.170)	4.100(1.287) ^a	2.083(1.283)	3.067(1.486)	3.375(1.847)	22.104 <0.001*
Study Skills	3.727(1.279)	3.850(1.226)	3.600(1.350)	4.083(1.139)	4.200(0.862)	4.125(1.136)	2.648 0.107
Peer Mentoring	3.909(1.269)	3.700(1.342)	4.000(1.247)	2.958(1.601)	3.267(1.387)	3.375(1.598)	6.575 0.012
Frequent Check-Ins from Support Staff	3.909(1.065)	3.900(1.224)	3.900(1.287)	3.500(1.383)	3.667(1.047)	3.875(0.835)	1.431 0.234
Support Groups with other disabilities	3.600(1.046)	3.600(1.046)	3.591(1.260)	2.792(1.444)	3.800(1.320)	3.250(1.581)	3.292 0.073
Social interaction opportunities	4.150(1.089) ^a	4.150(1.089)	4.091(1.151)	3.292(1.546)	3.400(1.454)	4.125(0.835) ^b	6.310 0.014
Modified Living Arrangements	3.900(1.165)	3.900(1.165)	3.455(1.471)	2.208(1.532)	3.000(1.512)	2.750(1.753)	15.482 <0.001*

Note:

^a = Top cited area of concern for individuals with ASD.^b = Top cited area of concern for individuals with ADHD.* = Significance at the *p* < 0.01 level.