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Students with Autism Spectrum Disorder in College: Results from a Preliminary Mixed Methods:

Needs Analysis

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Abstract

Background—There is a growing call for empirically based programming to support the success of students with autism spectrum disorder (ASD) as they transition to college.

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Aims—The purpose of this study was to identify the needs and challenges faced by adolescents and young adults with ASD in postsecondary education.

Methods—A mixed methods approach was taken to explore the needs of college-bound and college-enrolled students with ASD. Primary stakeholders (i.e., parents, educators/support staff from secondary and postsecondary institutions, and students) participated in an online survey ($n = 67$) and focus groups ($n = 15$).

Results—Across the stakeholder groups, commonly identified areas of difficulty included limited interpersonal competence, managing competing demands in postsecondary education, and poor emotional regulation. There was a high degree of agreement across stakeholders in the identified needs and challenges.

Implications—Findings from this preliminary needs analysis will inform the development of programming to support students with ASD.

Keywords

autism; college; adult; transition; self-determination

It is estimated that as many as one in 68 children meet diagnostic criteria for an Autism Spectrum Disorder (ASD; United States Center for Disease Control and Prevention, 2014). The diagnosis is usually stable from childhood to adulthood (Magiati, Tay, & Howlin, 2014). Although many individuals with ASD have co-occurring intellectual disability, the rate of diagnosis has increased dramatically among those without intellectual disability (e.g., VanBergeijk, Klin, & Volkmar, 2008). Approximately half of the population diagnosed with ASD has average to above average intellectual ability (United States Center for Disease Control and Prevention, 2014). As such, there are many adolescents and young adults with ASD who are intellectually capable of earning an advanced degree.

Despite intellectual capability, young people with ASD are less likely to enroll in postsecondary education (2-year or 4-year) than are peers with most other types of disabilities, such as speech/language impairments and specific learning disabilities (Wei, Yu, Shattuck, McCracken, & Blackorby, 2013). Whereas most (approximately 59%) of non-disabled students who enroll in four-year colleges ultimately graduate with a Bachelor's degree (National Center for Education Statistics, 2014), only about 41% of individuals with a disability, including ASD, graduate (Newman et al., 2011) from a Bachelor's granting institution. At this time, no reports on college graduation rates for students with ASD specifically have been published.

Low levels of educational attainment are associated with later disadvantage in the work place. Most adults with ASD are neither consistently nor gainfully employed (Engström, Ekström, & Emilsson, 2003). When employed, they tend to be paid less than young adults with other, non-ASD disabilities (Roux et al., 2013). Generally, quality of life is also relatively poor (van Heijst & Geurts, 2015) and social inclusion remains limited in adulthood (Howlin, Moss, Savage, & Rutter, 2013). Paradoxically, adults with ASD without co-occurring intellectual impairments are at increased risk for adverse outcomes, skill loss, and inadequate services and supports relative to those with comorbid intellectual disability

(Taylor & Seltzer, 2011). They face a host of challenges including limited access to appropriate or subsidized services, despite their many difficulties in living independently (Mazefsky & White, 2014; Taylor & Seltzer, 2011).

Programming to support a smooth transition from high school to postsecondary education may prove critical in helping students succeed in the postsecondary environment, as well as preventing a host of adverse outcomes (i.e., skill loss, symptom exacerbation, and poor quality of life, in adulthood). Transition to postsecondary education typically occurs during late adolescence and early adulthood, a developmental period of heightened risk for people with ASD. Core ASD symptoms (e.g., social and communication impairment) and daily living skills tends to plateau, or sometimes worsen, after adolescence (Smith, Maenner, & Seltzer, 2012; Taylor & Seltzer, 2010), so intervening during this period may be especially beneficial with respect to longer term outcome.

To optimize student success as well as program dissemination, transition programming should be participant-driven. In other words, input from the end-users should help ensure that the most salient needs of students with ASD are addressed. Additionally, end-user input will increase the likelihood that the final program is structured in such a way that college-based disability services offices can implement the program as intended (with fidelity) and with minimal additional cost of staff, so that it is sustainable. Van Hees and colleagues (2014) assessed the self-identified challenges of college students with ASD via semi-structured interviews with 23 current college students. They surmised that the successful balance of three major domains of student life (i.e., education, socialization, and independent living) posed the greatest difficulty, rather than a single skill deficiency or life challenge (Van Hees et al., 2014). It was concluded, therefore, that multifaceted supports are likely to be more effective than those targeting only one domain, such as academic success. For instance, Gelbar and colleagues (2015) investigated the experiences of college students with ASD by conducting an online survey with 35 adults with ASD who were previously or currently enrolled in college. They found that students tended to receive considerable academic supports and accommodations, but lacked supports for social and emotional difficulties. Most recently, Cai and Richdale (2016) conducted focus groups with 23 students with ASD in postsecondary education and 15 family members. They found that students perceived receiving better educational than social supports, whereas family members reported inadequate supports in both the academic and social domains. Research has yet to assess the perspectives of school personnel who work with students with ASD during transition and while in postsecondary school.

Although interest in the experiences and needs of college students with ASD has risen in recent years, the research base in this area is limited. What is known comes primarily from case studies and surveys of affected college students (Gelbar, Smith, & Reichow 2014) and autobiographical accounts written by high-functioning adults with ASD (Carley, 2008; Robison, 2008). The purpose of this preliminary study was to further develop our understanding of the needs faced by college students with ASD, as well as those who are college-bound, via qualitative and quantitative assessment with all three stakeholders who are most invested in this issue: parents of students with ASD, educators at the secondary and postsecondary level, and the students themselves. As such, this serves as the first mixed

methods approach to understand this population's needs, based on the perspectives of all the primary stakeholders.

Methods

The study utilized a mixed methods design comprising both focus group and survey methodology. Qualitative methods are often considered ideally suited for early inquiries into a new area of research, in which there exists too little theory or prior research to guide hypothesis generation (Palinkas, 2014). A focus group design was implemented to extract participants' beliefs, attitudes, and opinions regarding postsecondary education for students with ASD. Focus groups are a useful tool in gathering exploratory data in the initial phase of a research study (Dawson, Manderson, & Tallo, 1993). Students and postsecondary school professionals shared their thoughts via a collaborative open-ended interview. In addition to the focus groups, individual surveys were developed to obtain quantitative data. The surveys were structured similarly so that responses from all three stakeholder groups could be compared.

Qualitative and quantitative methods can be used simultaneously to provide complementary perspectives on an issue or question, as they provide depth and breadth of understanding, respectively (Palinkas, 2014; Yardley & Bishop, 2007). The focus groups and online surveys were implemented in parallel and data analyzed independently, allowing for a richer understanding of the phenomenon under study while preserving the integrity and unique elements of each methodological approach (cf, Yardley, 2008). Ethical approval was obtained from the investigator's university.

Participants

Focus Groups—Participants were recruited over a one-month period through autism-specific email listservs and newsletters, school personnel at the community college and university level, college student-directed outreach efforts, and personnel contacts. Inclusionary criteria for the student focus group consisted of: 1) full or part-time enrollment in a postsecondary 2-year or 4-year placement and 2) a self-disclosed ASD diagnosis. Inclusionary criteria for the school personnel focus group consisted of: 1) employment at a 2-year or 4-year institution and 2) self-disclosed experience working with students with ASD. Respondents were each offered a \$10 cash honorarium for their participation in a group.

Five full-time students (age range, 19–26 years) from the same large, public four-year university participated in one focus group. Academic majors included engineering ($n = 3$), chemistry ($n = 1$), and environmental science ($n = 1$). At the time of the focus group, all student participants received some form of academic or other support at their postsecondary institution. Participants all self-identified a diagnosis of ASD with varied initial diagnosis ages ($M = 18.6$ years, range = 9 – 26). Although this is a fairly late mean age of initial diagnosis, ASD is often identified later in adolescence for individuals of high cognitive ability (e.g., White, Ollendick, & Bray, 2011). The group was comprised of individuals at different academic stages (freshman to graduate student). Two focus groups were conducted with postsecondary school personnel. Educators and support staff from a two-year college

participated in the first group, and educators and support staff from a four-year university were in the second group. Five participants were present at each interview and represented a variety of professions such as disability office support staff and academic classroom lecturers. Demographic data on focus group participants is provided in Table 1.

Online Survey—The online surveys were made available nationwide and participants were recruited through a variety of means, including posted fliers, emails to ASD-specific organizations and groups, and a network of university-based educators and researchers who specialize in ASD. The parent survey was open to parents of adolescents and young adults with ASD aged 16 to 25. Similarly, individuals with ASD in this age range were eligible to complete the student version of the survey. The school personnel survey could be completed by any professional with experience in working with individuals with disabilities in a high school and/or postsecondary institution. Although no exclusionary criteria were in place regarding verbal or intellectual ability (of the students with ASD), the description of the study indicated that it was to gauge perspectives on transition into postsecondary education. Survey responses were anonymous and secure. Respondents were given the option of receiving a \$10 honorarium which was awarded as an electronic gift card. The school personnel survey was completed by 30 participants. See Table 1 for demographic information of survey respondents.

Data Collection and Analysis

Focus Groups—Three distinct focus groups were conducted, two with school personnel and one with students. The content and structure of focus group questions were comparable across all groups. Prior to each session and following informed consent, the collaborative nature of the focus groups was explained and participants were given the option to withdraw or refrain from answering questions at any time. All interviews were held in a conference room at an academic institution and led by the same person to ensure consistency. In each group, there were seven to nine seed questions posed (see Appendix 1), all of which were related to achieving success in higher education (e.g., “What has been most helpful to you in your schooling so far?”). Focus group questions were derived from the relevant literature (e.g., Duke et al., 2013) and refined by 2 co-authors and 1 expert in the field of qualitative research methods for clarity and content after initial pilot testing. Due to the minimal research assessing student or school personnel stakeholders, an exploratory methodological approach was adopted with the purpose of informing future studies. The student focus group lasted 49 minutes and the school personnel groups averaged 48 minutes. The structure of the focus group followed gold-standard guidelines and recommendations for the conduct of such groups (Grudens-Schuck, Allen, & Larson, 2004; Krueger & Casey, 2015; Krueger et al., 2001).

Focus groups were audio-recorded and transcribed in full. Subsequently, data from the transcripts were subject to line by line frequency coding of overarching themes by two independent researchers. The coding scheme was informed by the line by line frequency coding 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 (see Figure 1 for a visual representation of codes). 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 (available upon request) was then applied to the full set of interviews. Two independent coders coded 35% of the transcribed focus groups and achieved a reliability Kappa of .80 (i.e., very high agreement; Landis & Koch, 1977). After agreement at this level was established, two coders independently coded the focus group transcriptions.

Online Survey—Separate surveys were administered to the three individual stakeholder groups: secondary and postsecondary school professionals, parents of students with ASD, and youth with ASD themselves. The surveys were largely comparable across respondents for the purposes of drawing thematic connections or discrepancies, but differed in some ways (e.g., school personnel were not asked about reasons for students not enrolling in postsecondary education or prior interventions). The survey was carried out using an encrypted and secure website link sent to participants who expressed interest in the study. All surveys also included validity check items (e.g., “Please select ‘2’ for this item.”) to identify careless responding. Survey content was derived from existing research (e.g., Gelbar et al., 2014) pertaining to the deficits, strengths, and areas of need found most commonly among young adults with ASD, in conjunction with expert consultation. Experts in the fields of adult ASD and educational transition were asked to provide feedback regarding survey content in order to ensure that the respondents’ input would be maximally informative for the purposes of transition support program development (e.g., breaking down the core deficits into targetable areas of intervention, inquiring about the utility and benefits of past services, determining interest in other specific potential supports). Survey questions about the severity of past challenges, usefulness of previously received services, interest in receiving additional services, or knowledge about ASD included specific examples and participants were asked to provide their ratings on a 5-point Likert scale, the specific anchors of which were tailored to fit each question.

We employed composite analysis, in which the qualitative and quantitative components of the study are analyzed separately and then integrated (cf, Yardley & Bishop, 2007). As such, data collection via the focus groups and surveys took place simultaneously. The findings of each approach then mutually informed our summative understanding of the needs and challenges of students with ASD. Thematic analyses were used to identify the primary themes brought out during the focus groups and the most frequently endorsed areas, across each stakeholder group, in the survey.

Results

Focus Groups

Four primary themes emerged from the focus group interviews. Code frequency was transformed into an intensity matrix which was used to derive the primary themes of the focus groups (see Table 2). Across both students and educators, Interpersonal Competence was cited as the biggest area of need among postsecondary students with ASD. Interpersonal

Competence was defined as listening, cooperating, and communicating effectively. Phrases such as, “they have trouble chatting [or with] small-talk” were noted. Subtle differences between the students and school personnel existed with regard to subsequent areas of need that were identified. Students themselves identified Instrumental Independence (i.e., organizing activities, problem-solving, and time-management) as a domain of need, secondary only to Interpersonal Competence. Consistent with this domain, student participants made comments such as, “I wish I knew how to manage my time better” and “the nonverbal social cues as part of a group project...they might be joking but you think they’re serious about what they’re saying and that can cause a lot of confusion.” Within the student group, specific emphasis was placed on difficulties with time-management and organization of materials. Additionally, students indicated that they had difficulty with Intellectual Competence and Keeping Pace, specifically manifested as problems navigating academic demands, classroom expectations and policies, and recognizing and managing difficulties with increasing workload. For example, students made comments such as, “I also have a hard time keeping up with the things I am supposed to be doing” and “I need time to think and they just want to do now, now, now.” Academic tasks such as note-taking were regarded as difficult in the postsecondary context, largely due to competing factors such as attention and time constraints.

Two-year and four-year postsecondary school personnel endorsed Emotional Independence as an area of weakness for postsecondary students on the spectrum. They identified that separating from the parent support system seems difficult for students with ASD. One school professional commented, “They are depending on parents to tell them what to do at every turn.” Likewise, school personnel indicated that students often exhibit behaviors that stem from being overwhelmed in the postsecondary environment. Although two-year and four-year postsecondary school personnel endorsed themes which were largely similar in nature, slight differences emerged with respect to perceived student challenges (i.e., students’ anxiety) and staff competencies (i.e., a need for tolerance of student differences). Specifically, four-year postsecondary school personnel indicated that they see students with “a lot” of anxiety and expressed an increased need for sensitivity to differences among students on the spectrum to assist in overall achievement.

Online Survey

School Personnel Responses—School personnel were first asked to rate their knowledge of ASD. Knowledge areas included: the fundamentals of ASD; diagnosis and identification; how ASD is unique; prognosis and outlook; and the types of supports needed by those with ASD. From among these areas, the lowest overall rating (reflecting less knowledge) was on the ‘prognosis and outlook for those with ASD’. Respondents were also surveyed on how important it was to them to learn more about helping students with ASD during the transition process. The findings suggest that they considered it most important to learn more about how to interact with students with ASD. Specifically, when asked to rate importance, 86.6% of respondents endorsed ‘how to interact with students on the autism spectrum’ as *considerably important* or *very important*. This was ranked higher in importance than ‘learning about prognosis and outlook’ (despite the fact that this was the lowest ranked area in terms of current knowledge). We also asked school professionals about

challenge areas faced by students with ASD during the transition process, with severity ratings. The areas assessed included 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. As indicated in Table 3, school personnel felt that students with ASD face the most difficulty with social interaction, lack of social supports, and self-advocacy. In addition to these areas, which were most frequently rated as serious or severe issues, participants were offered the chance to provide open-ended qualitative feedback. Those who opted to elaborate further described the need for close guidance and support, tempering students' unrealistic expectations about their progression through postsecondary education, and implementing all of the necessary skills (e.g., self-advocacy, social motivation, focus) in a nuanced and context-appropriate way.

School personnel were also asked to rate how helpful they considered various services (e.g., academic tutoring, speech/language services and therapies, assistive learning technologies) for students transitioning into postsecondary school. As shown in Table 3, those who work closely with adolescents and young adults with ASD in school settings most often felt that devoted transition services, social interaction training, and emotion regulation therapy would be most beneficial to promoting adaptive functioning. Finally, school professionals were asked about their interest in receiving training in specific areas related to assisting students on the spectrum. From among the available choices (i.e., education on ASD, legal rights, the transition process, minimizing gaps in services, and accessing resources), training on how to access specific resources for students facing transition was the most highly sought.

Parent Responses—The eight parent respondents with children in postsecondary education were asked to rank five factors (i.e., location, academic reputation, available supports for students with disabilities, cost, and personal match in terms of diversity or size) that may have affected their son or daughter's decision when choosing a postsecondary institution. Academic reputation and location (e.g., being close to family) were each ranked highest by three parents. The seven parents who indicated that their young adult was not enrolled in any type of formal schooling at the time of the survey all noted that their children had never attempted college. Three reasons for non-enrollment emerged, one of which was endorsed by the majority of parents. Most (Six of the seven parents; 86%) indicated that their young adults' uncertainty about what they wanted to do played a role in the decision not to enroll in postsecondary education. Another reason was that the young adult opted instead for a job (endorsed by three of seven; 43%). Finally, three parents rated the student's concerns about not being able to do well as a reason for not pursuing higher education. With respect to the perceived challenges faced by young adults with ASD during transition, parents rated social interaction and inadequate social supports as prominent challenges, but also endorsed limited adaptive skills among the top difficulties (Table 3).

Table 3 also illustrates the parent stakeholders' rankings of service need. Although parents, like school personnel, ranked transition services in the top three, the need for social opportunities was most often endorsed, and independent living training was also high-ranking. Interestingly, among the additional services desired (by parents for their adult

children), group-based programs that incorporated both students with and without ASD was a frequent suggestion. Parents also described the need for some form of individualized intervention that could address the larger picture of each student's deficits. Open-ended feedback provided by parent respondents suggested that, although many of students with ASD demonstrate social motivation, problems with anxiety and deficits in perspective-taking complicate interpersonal situations. Several parents mentioned that even slight deviations in social situations might prompt emotional outbursts which would not be conducive to success in postsecondary education.

Student Responses—With regard to challenges the students themselves have experienced upon transition out of high school and into postsecondary school, respondents were asked to rate the same list of difficulties presented to the parent and school respondents. Students reported that the reduction in social supports, the academic stress, and the difficulty managing intense emotions were their greatest challenges. Students were also asked about services in which they were most interested, assuming there were no financial costs or added burden (see Table 3). Open-ended feedback provided by the students indicated that past conflict with teachers, and variability in school personnel level of understanding and sensitivity, as factors contributing to their apprehensions about college. Another major concern reported was balancing the overwhelming number of daily living responsibilities and social demands while focusing on school.

Discussion

Despite a growing population of college-bound young people with ASD, there is surprisingly little research on their needs, particularly with the aim of informing future intervention efforts. We lack emic guidance, or perspectives from all of the core stakeholders, on how to best support these students in achieving academic and social success once in college. This study presents findings from a mixed method needs analysis undertaken to inform development of transition support programs. Perspectives from students (the intended end-users), their parents, and secondary and postsecondary educators (e.g., case managers, teachers) are critical to developing practical and effective programs and supports (Kochhar-Bryant, Bassett, & Webb, 2009). Indeed, understanding the end-users' perceptions and experiences is valuable in developing and refining any intervention or support program (Chambers et al., 2007).

The most frequently endorsed service needs from the online survey and the central themes that emerged from the focus groups reflect challenges in many areas, including emotion regulation and stress management, socialization, transition to adulthood/independence, intimacy, and academic demands. These specific areas can be grouped into three broad categories – social needs, self-determination needs, and self-regulation needs (see Table 4). These three categories, and their associated challenges, are consistent with the extant research in adult transition as well as the wider research base on core impairments that are characteristic of ASD.

Social difficulties were identified as a central need across stakeholders, highlighting the importance of approaches to facilitate age-appropriate social interaction, without the help of

parents or teachers. Within this domain, specific challenges related to developing interpersonal competence and age-appropriate capacity for intimacy, as well as lack of social supports were identified. Social impairments are pervasive in ASD (e.g., White, Koenig, & Sahill, 2007) and clearly affect a student's successful transition into postsecondary school (e.g., Gelbar et al., 2015). Difficulties with navigating a new, often overwhelming and large, social environment must be addressed as students transition to postsecondary education (Wenzel & Brown, 2014).

In addition to the core social challenges diagnostic of ASD, identified challenges pertaining to self-determination (e.g., uncertainty about future, advocating for needed accommodations, independent living skills) are particularly germane to this developmental phase. In this domain, concerns with developing skills to function as independent adults (training in daily living skills) and developing a stable identity were noted. Some of the most frequently identified challenges include maintaining motivation for school, time-management, organization of materials, and managing intense emotions and academic stress. The importance of self-determination, or the ability to identify and achieve one's own goals (Field & Hoffman, 1994), has long been recognized in educational practice and policy related to students with disabilities (Ankeny & Lehmann, 2011; Cobb, Lehmann, Newman-Gonchar, & Alwell, 2009). Self-determination improves post-school outcomes for students with disabilities (e.g., Chambers et al., 2007; Solberg, Howard, Gresham & Carter, 2012; Wehmeyer & Palmer, 2003). Knowledge about one's disability, as well as associated strengths and difficulties, is critical to self-determination. Similarly, research has shown that limited self-knowledge impedes students' ability to advocate for themselves (Hitchings et al., 2001; Webster, 2004). Intervention studies that have sought to enhance self-determination have generally reported significant, positive effects (Chambers et al., 2007). To date, however, only one study on a self-determination enhancement program for high school students with ASD has been published (Fullerton & Coyne). In that study, eight adolescents and adults with ASD demonstrated increased knowledge and self-determination skills following a 10-week class.

The third and final category of identified needs and challenges related to self-regulation (e.g., time management, emotion modulation). Self-regulation is a multifaceted construct that involves monitoring, oversight, and modulation of behavior, emotion, and cognition (Baumeister et al., 2007; Karoly, 1993). Self-regulatory ability is important to achieving 'fit' or harmony between self and the external world (Baumeister, 1998). It is closely related to executive functioning capacity (e.g., one's ability to update and monitor information, and inhibit prepotent responses; Bridgett et al., 2013). Ability to regulate the experience and expression of one's emotions, and adapt in the moment in the service of identified goals (i.e., goal-directed behavior; Thompson, 1994), is part of self-regulation (Bridgett et al., 2013). Problems with self-regulation, including executive function and emotion regulation impairments, are commonly ascribed to individuals with ASD (Corbett et al., 2009; Hewitt, 2010; Mazefsky & White, 2013). These deficits manifest in a host of problems, such as inflexibility in routines, poor inhibitory control and time management, lack of motivation or impaired goal-directed behavior. There is also growing consensus that the high rates of psychiatric comorbidity reported among adolescents and adults with ASD may stem, in part, from impaired emotional regulation (Mazefsky et al., 2013).

We propose that developing students' skills in all three of these domains (socialization, self-determination, and self-regulation) should positively impact readiness for transition and adjustment to college, for secondary and postsecondary students, respectively. Focused skills training and preparation in anticipation of the transition, along with supports within the postsecondary setting, should promote smoother transition from secondary school, and better outcomes with respect to quality of life, academic and social success, and symptomatic impairment.

Although there was considerable convergence across the stakeholder groups with respect to themes that emerged, there was not uniform agreement across school personnel, parents, and students with respect to ranking of the relative importance of needs. For example, school personnel identified a considerable need for greater self-advocacy in the students, yet neither the students nor the parents identified this among their top three needs. It may be that school personnel have a deeper appreciation for the value of self-advocacy. As such, college-bound or college-enrolled students with ASD may benefit from explicit training to develop advocacy skills, and perhaps practice *with* identified school personnel could support this development. School personnel also identified a need for more training and assistance on how to help facilitate transition out of secondary school for students with ASD, including connecting families with appropriate resources and gaining knowledge about educational and career paths most fitting for individuals with ASD.

Although this pilot study is novel in its multi-method approach and consideration of all three stakeholder groups, results must be considered preliminary in light of the small sample size for both the focus groups and the online survey. We were only able to employ one student focus group and no parent focus group, which limited our ability to reach saturation of themes (e.g., Krueger & Casey, 2015). Despite concerted efforts to encourage student participation, the results presented herein for the survey primarily represent the parent and school personnel. Reliance on parent-report data in research with adults with ASD is fairly common (e.g., Smith et al., 2012; Taylor, Smith, & Mailick, 2014); nevertheless, the limited voice of the students with ASD themselves in this study's results must be emphasized. Students in this study were predominantly enrolled in postsecondary education and, as such, it will be important to determine if these findings apply to students with ASD still facing the transition out of high school. The themes that emerged from the focus groups converged with those identified from the survey data and, collectively, these data provide a complementary perspective (primarily that of parents and school personnel), to recent research that focused on the needs as identified by postsecondary students (e.g., Cai & Richdale, 2016). These preliminary findings offer early guidance to the field with respect to what should be included in programs designed to promote successful transition to postsecondary school for students with ASD.

Participatory research is critical to overcoming health care disparities for people with ASD (e.g., Nicolaidis et al., 2011), and there has been minimal research to inform transition support services. A participatory process approach was employed to identify the needs and challenges of students with ASD in postsecondary education. Results suggest that students entering postsecondary education face challenges in the domains of social integration, self-determination, and self-regulation. We posit that addressing each of these domains is

important for achieving optimal outcomes related to college adjustment (for those in postsecondary education), transition readiness (for those preparing for postsecondary education), and functional independence.

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Appendix A

[READ VERBATIM]

Hello and welcome. My name is (INTERVIEWER 1). I am a researcher in the Psychology department at [OMITTED FOR REVIEW] and I will be guiding today's conversation. (NOTE TAKER 1) and (NOTE TAKER 2) will be transcribing our discussion. Today, we will be talking about the needs, strengths, and challenges of students who are diagnosed with an Autism Spectrum Disorder (ASD). The purpose of today's discussion is to gather your opinions and perspectives. Therefore, there are no right or wrong answers. We ask that you be respectful of all of the group members here today and allow for a collaborative discussion.

In order to facilitate a timely session, I may kindly ask you to finish a thought so all questions can be adequately addressed. The session is expected to last approximately 1 hour.

Additionally, this focus group will be taped with an audio recorder for later data analyses. All content discussed within the group today is confidential and compliant with the Virginia Tech institutional review board guidelines. We ask that all individuals here today respect the privacy of their peers by not discussing content outside of this focus group.

You can stop at any time and without penalty, by telling the researchers that you want to stop the study. If you decide to not participate or to withdraw from the study, your involvement in any future study will not be jeopardized.

Does anybody have any questions before we begin?

College Students with ASD

1. Tell us about yourself – your first name, year in college, your major
2. What do you think of your experience in college so far? (If probes are needed: what have you enjoyed? What do you like to do?)
3. What are some of the challenges you face as a college student with ASD?
4. Think of possible supports, services, and interventions. What do you wish you had access to now?
5. What has been most helpful to you in your schooling so far?
6. What strengths do you have that help you succeed in college?

7. [IF TIME] What would you like to tell the ‘young you’ (or people with ASD who are contemplating going to college)?
8. [IF TIME] What are the easiest aspects of college life?
9. What helped you transition from high school to college?

School Personnel/Educators

1. Tell us about yourself – your first name, your job title, the type of institution you work at (i.e., 2 yr/4yr college)
2. Please talk about your experience in working with 16–25 year old students who have ASD
3. What do you see as the biggest hurdles, or challenges, encountered by students with ASD preparing to transition out of high school and into post-secondary schooling? (please think about the students themselves and their parents or caregivers)
4. In your experience, what are some strengths that you see in students who have ASD?
5. What areas of life and schooling are most problematic, where they may need the MOST help?
6. If money and staff were no issue, what types of supports and services would you like to be able to provide to help students with ASD transition out of high school and into post-secondary education?
7. [IF TIME] What would you like to tell parents of students with ASD about transition (e.g., what they should plan for and help with)?

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Highlights

- Diminished interpersonal competence is a central challenge of secondary/postsecondary students with ASD.
- Managing competing demands and poor emotional regulation are also challenges.
- School personnel cited greater self-advocacy as a primary student need.

What this paper adds?

The number of young adults diagnosed with autism spectrum disorder (ASD) is growing at an unprecedented rate. Many of these young adults graduate from secondary school unprepared for higher education or gainful employment, which can adversely affect quality of life and ability to live independently. In this paper, we describe the results of an initial mixed methods needs analysis, which was undertaken to examine the challenges faced by adolescents and young adults preparing for transition to postsecondary education and those who are enrolled in college, as perceived by the three primary stakeholder groups- parents, educators, and the students themselves. The content of this manuscript is novel, as there is very little research on the needs of these students as perceived by themselves, their parents, or school-based professionals, regarding the transition into postsecondary education.

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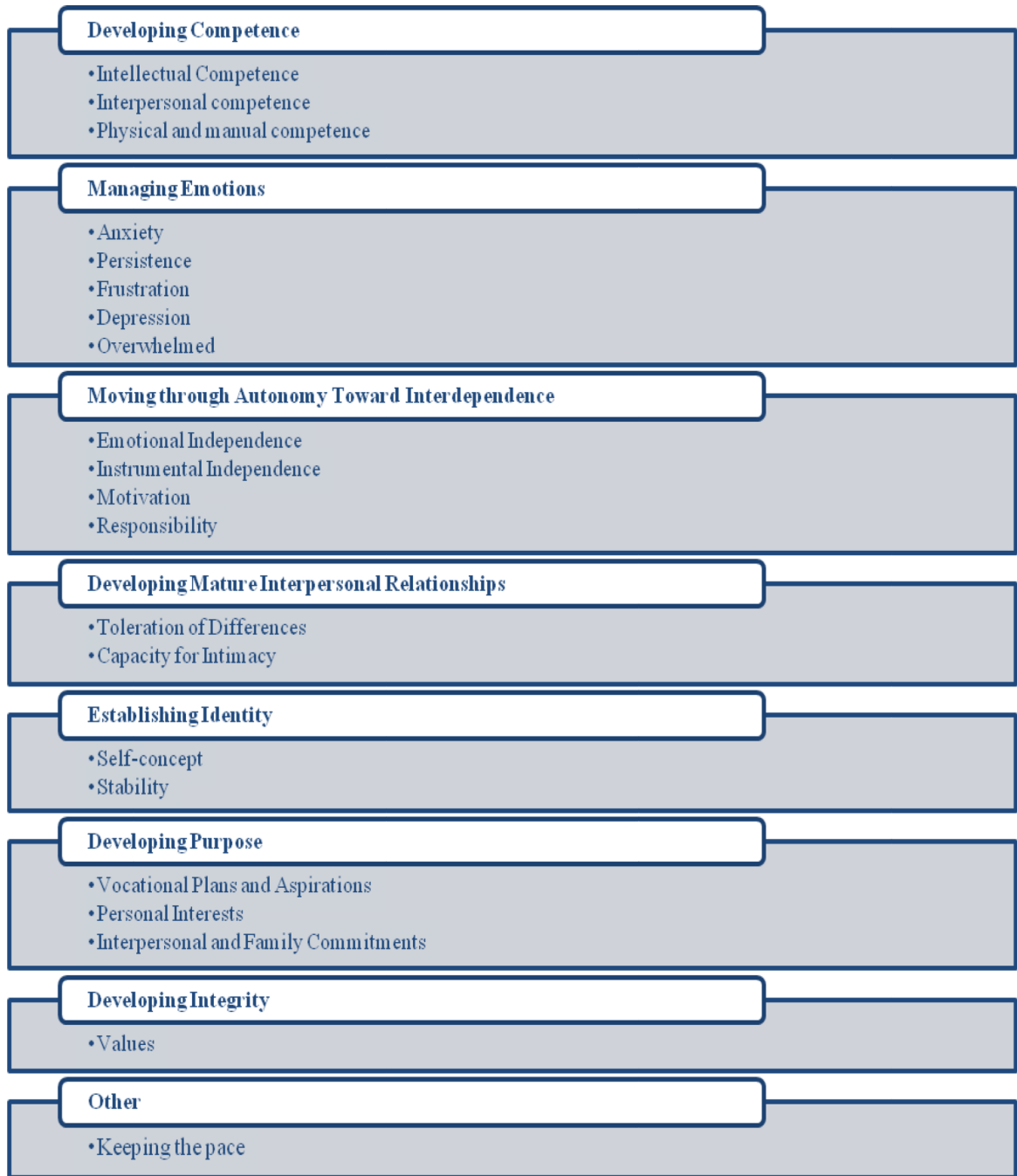


Figure 1.
Summary of the coding manual categories

Table 1

Participant Demographics

	Students	Parents	School Personnel
	Survey / FG <i>n</i> = 5 / <i>n</i> = 5	Survey / FG <i>n</i> = 32 / <i>n</i> = 0	Survey / FG <i>n</i> = 30 / <i>n</i> = 10
Gender			
Male	4 / 3	2 / --	5 / 2
Female	1 / 2	25 / --	25 / 8
Did not indicate	0 / 0	5 / --	0 / 0
Institution			
Secondary School	1 / 0	17 / --	15 ^a / 0
Specialized or Vocational School	1 / 0	0 / --	2 / 0
Community or 2-year College	0 / 0	1 / --	2 / 5
4-year University	3 / 5	7 / --	0 / 5
Other or None	0 / 0	7 / --	7 / 0
Student Mean Age (yrs.)	18.40 / 18.60	18.63 (2.21) / --	- / --
Race/Ethnicity			
White	4 / 3	15 / --	27 / 9
Black or African-American	1 / 1	7 / --	1 / 0
American Indian	0 / 1	0 / --	0 / 1
Hispanic or Latino	0 / 0	1 / --	0 / 0
Asian or Asian American	0 / 0	2 / --	1 / 0
Multiracial	0 / 0	1 / --	1 / 0
Did not indicate	0 / 0	6 / --	0 / 0

FG: Focus Group;

^aThree school personnel endorsed being affiliated with both an elementary school and a secondary school.

Intensity Matrix of the Frequency of Codes within Each Category Identified During Focus Groups

Table 2

Number of endorsements by participant type					
	2-year SP	4-year SP	Student	Total	
Developing Competence	Intellectual competence	7	2	11	20
	Interpersonal competence	14	45	35	94
	Physical and manual competence	0	1	0	1
Managing Emotions	Anxiety	1	13	3	17
	Persistence	3	5	5	13
	Frustration	1	2	3	6
	Depression	0	1	1	2
	Overwhelmed	5	10	2	17
Moving Through Autonomy Toward Interdependence	Emotional independence	7	17	8	32
	Instrumental independence	4	8	14	26
	Motivation	0	2	0	2
	Responsibility	1	8	10	19
Developing Mature Interpersonal Relationships	Tolerance of Differences	1	9	5	15
	Capacity for intimacy	3	6	3	12
	Self-Concept Stability	3	2	2	7
Establishing Identity	Stability	0	1	2	3
	Vocational plans and aspirations	1	1	0	2
	Personal interests	2	2	8	12
Developing Purpose	Interpersonal and family commitments	1	1	1	3

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Number of endorsements by participant type					
	2-year SP	4-year SP	Student	Total	
Developing Integrity	Values	0	0	0	0
	Other	1	0	11	12
	Keeping pace	0	0	1	1
	Taking risks	0	1	4	5
	Physical space	0	1	2	3
	Decision-making	0	1		

Note: SP: School Personnel. The numbers reflect the frequency of codes within each category.

Table 3

Challenges and Service Needs Most Frequently Endorsed from Online Survey Data

Stakeholder	Greatest Challenges		Most Helpful / Needed Services	
	Challenge	<i>n</i> (%) ^a	Service	<i>n</i> (%) ^b
School Personnel (<i>n</i> = 30)	1. Social Interaction	27 (90.0%)	1. Transition Services	28 (93.3%)
	2. Social Supports	26 (86.7%)	2. Social Interaction Training	28 (93.3%)
	3. Self-Advocacy	22 (73.3%)	3. Emotion Regulation Therapy	23 (76.7%)
Parents (<i>n</i> = 32)	1. Social Interaction	21 (65.7%)	1. Social Opportunities	25 (80.7%)
	2. Social Supports	16 (50.0%)	2. Transition Services	24 (77.4%)
	3. Adaptive Skills	16 (50.0%)	3. Independent Living Training	23 (74.2%)
Students (<i>n</i> = 5)	1. Social Supports	3 (60.0%)	1. Career Counseling	4 (80.0%)
	2. Academic Stress	3 (60.0%)	2. Weekly Supportive Therapy	3 (60.0%)
	3. Intense Emotions	2 (40.0%)	3. Social Interaction Training	3 (60.0%)

Note:

^a *n* refers to the number of individuals who rated the item as being either a 4 (usually a problem; serious issue) or a 5 (always a problem; severe issue).

^b *n* refers to the number of individuals who rated the service as being either a 4 (very helpful) or 5 (extremely helpful).

Table 4

Primary Needs Identified by Needs Analysis across Online Surveys and Focus Groups

Over-arching construct	Specific facets
Social integration	Navigating social interactions Finding social support Handling conflict with others
Self-determination	Finding transition services Self-advocacy Time management Sustaining or developing social motivation Goal attainment Self-awareness and knowledge Independent living skills
Self-regulation	Managing social, daily living, and social concerns Navigating inconsistencies and changes in routine Managing intense emotions Executive functioning (e.g., managing inattention) Coping with academic stress

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