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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. 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.

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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

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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.

1. Introduction

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 Centers 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 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, Moyson, and Roeyers (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 et al. (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.

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