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Review

A systematic literature review of the experiences and supports of students with autism spectrum disorder in post-secondary education



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ABSTRACT

Background: Post-secondary students with ASD experience a range of academic and non-academic difficulties and represent approximately one percent of the post-secondary cohort. The purpose of this review is to conduct a systematic literature review of articles that examined the barriers, challenges, and benefits experienced by post-secondary students with ASD, and the supports and services provided to them, and also to analyze student satisfaction with those supports.

Method: Three databases were searched and articles were screened against eligibility criteria.

The twenty-three studies (reported in twenty-nine articles) that met criteria were also assessed for quality. Data pertaining to the benefits, challenges, and barriers experienced, and student satisfaction with supports and services provided, were extracted and analyzed.

Results: The studies highlighted the diverse range of social, emotional and sensory difficulties experienced by students with ASD, and how those difficulties negatively impacted all aspects of their post-secondary education. Also, the supports provided were often incongruous with need and produced idiosyncratic benefits, demonstrating the need for individualized supports and novel solutions to be identified. Suggestions for future research were made.

Conclusions: While prior research on post-secondary students with ASD is limited and geographically circumscribed, the current body of research suggests that students with ASD are often more concerned with non-academic issues than with their academic studies. Also, many post-secondary educational institutions were found proficient at providing traditional academic supports while non-academic supports and resources were often found inadequate. In addition, many students with ASD experienced anxiety or had poor advocacy skills and this impeded their ability to access available supports. Finally, students with ASD were found to be very diverse and to experience idiosyncratic responses to supports, suggesting that supports ideally needed to be individualized, ubiquitous, and continually monitored.

The prevalence of autism spectrum disorder (ASD) is approximately one in 68 (Centers for Disease Control and Prevention (CDC, 2014) and almost half (46%) have average through to gifted intelligence (CDC, 2014). In addition, adolescents with ASD have expressed a strong desire to attend post-secondary education (Camarena & Sarigiani, 2009). This goal is increasingly being realized as between 0.7 and 1.9 percent of college students in the United States have been found to meet the criteria for ASD (White, Ollendick, & Bray, 2011). Nevertheless, a report commissioned by the US Department of Education found students with ASD in the

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U.S. have one of the lowest rates of enrolment (44%) at any post-secondary institution when compared with the general population (67%) and all disability groups (60%) (Newman et al., 2011).

The characteristics of post-secondary students with ASD can be diverse and paradoxical. They may possess significant strengths such as a strong memory, original and creative thought patterns with good attention to detail, and a single minded and determined nature, coupled with intense narrow interests (Drake, 2014a; Gobbo & Shmulsky, 2012). However, co-occurring atypical communication and social behaviours, an aversion to change and restricted interests (*The Diagnostic and Statistical Manual of Mental Disorders*, 5th ed.; DSM-5; American Psychiatric Association [APA], 2013) may negatively impact these strengths. Further, post-secondary students with ASD may be prone to loneliness, anxiety and depression (Mazurek, 2014), have difficulty interpreting or using verbal and non-verbal communication (Glennon, 2001; Pinder-Amaker, 2014), and they may have difficulty with time management and sensory sensitivities (Gobbo & Shmulsky, 2014; Pinder-Amaker, 2014).

The extant literature has revealed that for some students with ASD post-secondary education was a positive experience that provided an opportunity to study in an area of intense interest and to meet likeminded colleagues; and that also led to employment (Drake, 2014a). However, it also revealed that many students with ASD struggle with asking questions, participating in group work, performing presentations, and understanding abstract or ambiguous concepts (e.g., Gobbo & Shmulsky, 2012; Knott & Taylor, 2014). In addition, some have been bullied (e.g., Connor, 2012), or experienced difficulty with daily living skills (e.g., Simmeborn Fleischer, 2012), or suffered severe mental health issues that caused them to withdraw or to reduce their enrolment (e.g., Knott & Taylor, 2014). Thus, a diverse range of issues face students with ASD and a more current review of the literature is needed to better understand the breadth of these key issues and their impact on the student educational experience.

Graduates with ASD have substantially better long-term income and employment prospects compared to non-graduates with ASD (Hendrickson, Carson, Woods-Groves, Mendenhall, & Scheidecker, 2013) and many countries have legal obligations to assist post-secondary students with ASD (e.g., s 22 of the *Disability Discrimination Act, 1992* [Cth; Australia]; s. 42 U.S.C. 12101 et seq of the *Americans with Disabilities Act [ADA; 2008]*). Support has been found to significantly improve graduation rates (White et al., 2011), however, graduation rates for students with ASD remain low. The graduation rate, for example, from any post-secondary institution in the U.S. (including 2-year community college, vocational, business or technical school, or 4-year college) was found by the National Longitudinal Transition Study-2 to be only 39% for students with ASD, compared with 52% for the general population and 41% for all students with disabilities (Newman et al., 2011).

The possibility of creating inclusive environments in school education has been demonstrated in research (Blamires & Gee, 2002), but there is limited research into the post-secondary educational experiences and needs of students with ASD. Indeed, only 6% of the extant literature on ASD examined participants older than 19 years (Jang et al., 2014), and research from the post-secondary student perspective is particularly scant (Gelbar, Shefcyk, & Reichow, 2015; Hastwell, Martin, Baron-Cohen, & Harding, 2012). Thus, there is little research guidance for academics and disability support personnel in post-secondary settings to inform best practice when providing support for students with ASD.

Gelbar, Smith, and Reichow (2014) provided the only systematic review of studies reporting on the experiences and supports available to students with ASD in post-secondary settings from the student perspective. They reviewed 18 studies (reported in 20 articles) with 68 unique participants who described the first-hand experiences and supports of students with ASD at college and university. Their review provided some interesting insights and had several strengths, but it also had a number of methodological weaknesses. They restricted their search to Medline, Embase (a biomedical and pharmacological database), and PsychINFO databases, missing some relevant studies, which were far more likely to be indexed in educational databases. Further, they used very broad inclusion criteria, that allowed articles without description of methodology or of data analysis, impeding interpretation of the relevant research and making replication impossible. Gelbar et al. acknowledged using a “liberal” definition of a case study that permitted studies with scant detail whose primary purpose was to support the author’s theoretical position (p. 2599). They did not strictly apply their own inclusion criteria and included articles where the participants did not have a diagnosis of ASD (Jurecic, 2007) or where first-hand accounts were not provided (Langford-Von Glahn, Zakrajsek, & Pletcher-Rood, 2008). In addition, they included studies that did not enable data on students with ASD to be separated from other participants (Griffin & Pollak, 2009), and their review was limited to studies in peer reviewed journals, with the attendant risk of findings being affected by publication bias (Schlosser, Wendt, & Sigafos, 2007). Moreover, Gelbar et al. did not study the strengths of students with ASD, nor the potential benefits attained from post-secondary education. Thus, the existing review had methodological and content limitations and may have resulted in an incomplete view of the experiences of post-secondary students with ASD. Given these issues, there is a case for re-examination of research on the experiences of individuals with ASD in post-secondary education.

The present review examined research that analyzed first-hand accounts of post-secondary students with ASD and addressed several of the methodological issues noted above. Specifically, the studies included in this review reported on descriptions provided by post-secondary students with ASD of their academic and non-academic experiences, and/or their satisfaction with the supports provided or used. The research questions were:

What were the post-secondary barriers, challenges, and/or benefits experienced by students with ASD and how did those experiences impact both academic and non-academic aspects of post-secondary education?

What supports and services were offered to assist students with ASD to complete their post-secondary education?

How satisfied were post-secondary students with ASD with the supports and services offered to them?

1. Method

The PRISMA (Preferred Reporting Items for Systematic reviews and Meta-Analyses) statement protocol, which includes a checklist

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