

Systematic Review of Articles Describing Experience and Supports of Individuals with Autism Enrolled in College and University Programs

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Abstract The increase in the number of higher-functioning individuals with autism spectrum disorders (ASD) is likely to lead to an increased interest in postsecondary opportunities including degree-granting college and university programs. To provide an understanding of the current evidence-base for supporting individuals with ASD in higher education, this article reports the results of a systematic review of the literature concerning college students with ASD. Overall, 20 articles describing 69 individuals met the inclusion criteria. This small number of articles and participants indicates the scarcity of research on this topic and only two of these studies were experimental in nature. These studies described a video-self modeling intervention and a counseling intervention respectively. Eighteen “case studies” were also present in the literature that described difficulties ranging from anxiety to housing concerns. This review delineates the limitation of our understanding of effective college programming for individuals with ASD.

Keywords Autism spectrum disorder · ASD · Asperger · College · University

Introduction

Autism spectrum disorders (ASD) are a family of complex neurodevelopmental disorders characterized by behavioral symptoms in two broad domains: difficulties with social

communication and the presence of restricted and/or repetitive behaviors (American Psychiatric Association 2013). Overall, ASD affects 1 out of 88 people (CDC 2012) and this prevalence rate indicates a significant increase in the number of individuals diagnosed with ASD over the past 10 years (Schieve et al. 2012; Volkmar et al. 2004). Many factors have contributed to the increasing prevalence rates of ASD including an increase in the number of individuals who are described as *higher-functioning* (CDC 2012). However, although individuals might be described as higher-functioning, the developmental trajectory of each individual is unique and the severity of symptom presentation may vary over time (Eaves and Ho 2008; Fein et al. 2013).

While the number of higher-functioning individuals with ASD is increasing, most of the research has focused on individuals who are lower-functioning (Van Bergeijk et al. 2008) and younger children (e.g., Reichow and Volkmar 2010). While the efficacy of early-intervention is well established (e.g., National Research Council 2001; Reichow 2012; Rogers and Vismara 2008), the paucity of research on older individuals has caused the Interagency Autism Coordinating Committee (IACC) to target transition programs for adolescence with ASD as a priority for research (IACC 2012). This emphasis on transition coupled with data on the poor post-school outcomes for individuals with ASD (Billstedt et al. 2005; Henninger and Taylor 2013) indicate the importance of research exploring experiences of higher-functioning individuals as they exit the K-12 education system.

Trends in recent research point to increased knowledge, awareness, and acceptance of individuals with ASD on college campuses (Gardiner and Iarocci 2013; Neville and White 2011; Tipton and Blacher 2013). In a survey with over 1,000 respondents, the majority indicated they were

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aware of the increase in prevalence of ASD, though they mistakenly attributed the increase to vaccinations (Tipton and Blacher 2013). This finding may reflect a broader trend in which campus communities are knowledgeable about the increased prevalence of ASD and trends in treatment, but remain less informed about etiology and outcomes (Gardiner and Iarocci 2013; Tipton and Blacher 2013). Quality of previous interactions with individuals with ASD have been shown to predict acceptance and willingness to volunteer to work with individuals with ASD, with females and social science majors particularly likely to volunteer and show acceptance (Gardiner and Iarocci 2013). A contradictory finding, however, indicated that social science majors were less comfortable interacting with individuals with ASD than engineering majors or students who had first-degree family members with ASD (Neville and White 2011).

Despite the increased awareness and acceptance of college students with ASD, their relatives have expressed concerns that these students were bullied, easily distracted, unable to prioritize, and lacked the ability to structure their schedules without the proper accommodations (Fleischer 2012). Relatives were further frustrated by their inability to play a role in the collaborative relationship between students and the disability services coordinators responsible for securing supports (Fleischer 2012). Additional work has described many of the academic challenges faced by individuals with ASD as they transition to postsecondary education. People have suggested that college counselors should act as the primary facilitators in coordinating supports among faculty, disability services offices, peer mentors and parents (Graetz and Spampinato 2008; Pillay and Bhat 2012). Although counseling and support services geared specifically towards students with ASD are rare, one exemplar program provided a first-year experience course unique to individuals with ASD consisting of an environment in which students can express concerns with their transition to college, practice social skills to facilitate improved peer interactions, and become familiar with campus facilities, procedures, and services (Smith 2007; Wenzel and Rowley 2010).

The difficulties with executive functioning and critical thinking faced by individuals with ASD can be addressed by using a variety of instructional strategies including breaking tasks into smaller pieces, providing clear expectations for submitted work, and helping students to make plans and stay organized (Shmulsky and Gobbo 2013). Additional academic accommodations that have been suggested include extended deadlines, extra time on exams, and alternatives to group projects and assignments involving public speaking (Gobbo and Shmulsky 2012). These types of supports allow students with ASD to demonstrate their knowledge of course material in a format

with which they are more comfortable. Difficulties with loosely structured courses and abstract language used by peers and professors have been addressed by providing detailed syllabi and using concrete language in lectures (Gobbo and Shmulsky 2012). Further, taking a reduced course load or scheduling classes only on certain days of the week has been suggested as a way to free students from the pressure of busy class days (Adreon and Durocher 2007). Finally, to address the hypersensitivities of many students with ASD, research has proposed the elimination of as many distracting environmental stimuli as possible (Gobbo and Shmulsky 2012).

In addition to academics, college students with ASD are likely to face issues with socialization, independent living skills (including housing and roommate concerns), self-advocacy, and structuring their time (Adreon and Durocher 2007; Fleischer 2012; Pillay and Bhat 2012). To address these concerns, utilization of independent agencies that provide services above and beyond those legally required by the Americans with Disabilities Act (ADAAA 2008) such as mentorship programs and weekly support group meetings has been proposed (Dillon 2007). Interventions designed to improve peer communication by developing scripted responses and practicing (role-playing) conversational skills have been described in the literature (Harrison 1998; Zager and Alpern 2010). Commuting from home to avoid the stresses of dorm life has also been proposed as a way to ease the transition to postsecondary education (Pillay and Bhat 2012).

As the number of individuals with higher-functioning ASD has risen (CDC 2012), the number of individuals with ASD seeking to attend degree-granting institutions of higher education is also likely to increase. Thus, it is essential to understand the current research base documenting the challenges and supports faced by college students with ASD to develop effective programs for high-functioning individuals with ASD in order to increase the post-school outcomes for this group. Unfortunately, the literature describing the intersection of ASD and postsecondary education has been limited. A review summarizing the available evidence does not currently exist so the purpose of this article is to provide a systemic review of the published literature on the firsthand experiences of individuals with ASD attending degree-granting colleges and universities.

Methods

Selection Criteria

We included articles in our review meeting the following inclusion criteria. First, the article contained individuals

with ASD who were attending a degree-granting college or university. Second, the article included a first-hand description of the services, supports, or experiences of one or more individuals. Third, the article was published in English in a peer-reviewed journal. Included and excluded studies were collected following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA; Moher et al. 2009).

Search Methods

We conducted an electronic database search of Medline, Embase, and PsycINFO in October 2013 using the following text word search strategy: (exp child development disorders, pervasive/OR autism* OR (pervasive development* disorder* OR PDD or PDDs) OR Asperger*) AND (undergraduate* OR college* OR university* OR (graduate adj student*) OR postsecondary). Two authors screened all titles and abstracts independently in order to exclude clearly irrelevant articles. The full papers of the remaining articles were then examined to determine which articles met all inclusion criteria. After the database search, we examined the reference lists of the included articles for possible articles that were not located in the database search.

Variable Definitions and Coding

For all articles, we attempted to code nine variables related to participant characteristics, college experiences, and services and supports received. We coded six variables related to the participants of the articles. First, we coded the location of the institution the participants were attending (United States, Canada, Great Britain, or other). Second, we coded the sample size of individuals with ASD in the article (individuals with developmental disorders other than autism were excluded). Third, we coded the participant's reported diagnosis (e.g., autism, high functioning autism, Asperger's syndrome, PDD, PDD-NOS). Fourth, we coded the gender (percent male) of participants. Fifth, we coded the mean, standard deviation, and range for the age of the participants. Finally, we coded the participant's full scale IQ.

We also coded three variables related to the college experiences and the supports and services described in each article. First, we coded firsthand experiences of the participants (e.g., depression, anxiety, difficulty making and keeping friends) that were described in each article. Second, we coded if the student received academic accommodations (e.g., note-taker, extended time on exams, separate test location) and/or curricular modifications (e.g., assignment substitution). Accommodations included any service provided by an instructor, peer, independent agency

or campus disability office that better allowed participants to complete the same coursework as peers in the same classes, whereas curricula modifications were changes in a course's syllabus that permitted a participant to complete different assignments than peers in the same class. Finally, we coded non-academic support services that were described (e.g., social support groups, peer mentors).

Results

Search Results

We located 3,553 records; 2,565 remained after deduplication. Fifty-one articles remained after title and abstracts were screened to ensure that the study focused on college students with ASD. Most of the excluded studies described or reviewed interventions or issues facing students in the K-12 education system. After examination of the full papers we judged 15 articles to meet all inclusion criteria. Examination of the reference lists of these 15 articles revealed an additional 52 articles for full paper examination, of which five met inclusion criteria. Thus, the final sample of articles was 20. The primary reasons for exclusion are shown in the PRISMA flow diagram shown in Fig. 1.

Article Characteristics

We located 20 articles published in peer-reviewed journals describing collegiate experiences and/or supports of adults with ASD. The articles were all published in or after 1999, which was over 50 years after Kanner's first description of infantile autism (Kanner 1943) and Asperger's initial description of the condition named for him (Asperger 1944). With respect to date of publication, one-half of the articles (50 %) were published since 2010. Of the 20 articles, all but one reported college experiences from the United States (11 of 20, 55 %) or the United Kingdom (8 of 20, 40 %); the one article not from the US or UK reported college experiences of one student from Japan (Yamamoto and Nihei 2008). The largest sample size of an individual article was 12 (Langford-Von Glahn et al. 2008). A majority of articles contained fewer than five participants (14 of 20 articles, 70 %). Two articles (Pugliese and White 2013; Mason et al. 2012) used experimental methods to investigate interventions. The remaining 18 articles (90 %) were essentially case studies of individuals with ASD in college.

Participant Characteristics

Table 1 provides information on participant characteristics, college experiences, and types of support services

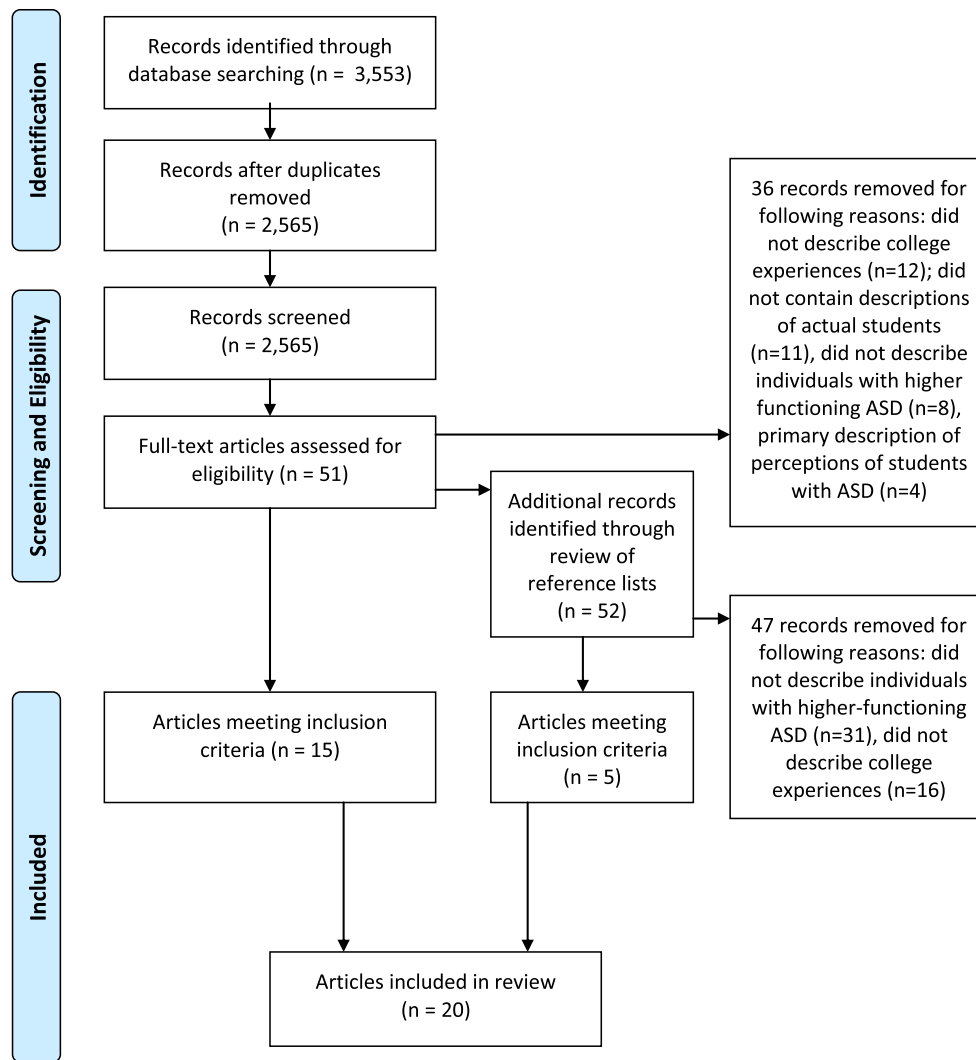


Fig. 1 Article inclusion decision tree (adopted PRISMA flow diagram)

across the articles included in this review. Collectively there were 69 participants across the 20 articles included in this review (there were the same eight participants in Madriaga (2010) and Madriaga and Goodley (2010) and the same single participant in Connor (2012, 2013) so they were only included once in the total count). All (100 %) articles provided diagnoses for participants, though one (Lee et al. 1999) was speculative in nature. Asperger's syndrome (52 of 69, 75 %) was the most prevalent diagnostic category, followed by ASD (12 of 69, 17 %) and PDD (5 of 69, 7 %). In articles that reported the gender of participants (17 of 20, 85 %), the majority (41 of 60, 68 %) were male. Age information of participants was included in five articles (25 of 69; 36 % of participants) with a range across articles of 16- to 30-years-old ($M = 21.20$, $SD = 3.20$). Full scale IQ information was provided in one of 20 articles (5 %) for five participants ($M = 128$, $SD = 9.50$).

College Experiences

Firsthand experiences of individuals with ASDs in college settings were described in 17 of 20 (85 %) articles and are shown by study in Table 1. Anxiety (12 of 17, 71 %) was the most commonly reported experience, followed by loneliness (9 of 17, 53 %) and depression (8 of 17, 47 %). Participants also described experiences of isolation/marginalization (e.g., peer rejection of participant's repeated social overtures, peers starting a petition to have a participant removed from a dormitory) in 4 of 17 articles (24 %). Housing and roommate concerns were reported in 3 of 17 articles (18 %).

Academic Supports and Services

The majority of articles (12 of 20, 60 %) described academic supports and services for the students with ASD and

Table 1 College experience and supports for students with autism

Study	Location	N	Diagnosis	Gender (M:F)	Age (years)	First hand experiences	Academic supports	Non-academic supports
Brazier (2013)	United States	1	Autism spectrum disorder	1:0	Not reported	None reported	Lecture notes, extra time on exams	None reported
Connor (2012)	United States	1	Asperger's syndrome	1:0	19	Loneliness, anxiety, depression, isolation, bullying	Separate location and extra time on exams	None reported
Connor (2013)	United States	1	Asperger's syndrome	1:0	19	Loneliness, anxiety, depression, housing/ roommate concerns	None reported	None reported
Glennon (2001)	United States	4	Asperger's syndrome	4:0	Not reported	Stress, housing/ roommate concerns	Professor facilitation of group work	Peer mentor, Social Stories counselor,
Griffin and Pollak (2009)	United Kingdom	6	Asperger's syndrome	5:1	Not reported	Loneliness	Lecture notes, extra time on exams, extended deadlines, tutor	Peer mentor
Jones et al. (2013)	United Kingdom	9	Autism spectrum disorder	6:3	Range 16–21	Bullying, marginalization, lack of understanding	None reported	None reported
Jurecic (2007)	United States	1	Asperger's syndrome	1:0	Not reported	Difficulty writing for an audience	None reported	None reported
Langford-Von Glahn et al. (2008)	United States	12	Asperger's syndrome	7:5	Not reported	Loneliness, anxiety, depression, academic difficulty, lack of understanding	Lecture notes and materials, coursework modifications, testing accommodations	None reported
Lee et al. (1999)	United States	1	Asperger's syndrome	1:0	21	Loneliness, anxiety, depression, academic failure, time management	None reported	None reported
MacLeod and Green (2009)	United Kingdom	2	Asperger's syndrome	2:0	Not reported	Anxiety, bullying	Tutor	Peer mentor, counselor, parent involvement, Social support group, disability team
MacLeod et al. (2013)	United Kingdom	6	Asperger's syndrome	3:3	Not reported	Marginalization	None reported	None reported
Madriaga (2010)	United Kingdom	8	Asperger's syndrome	5:3	M = 21.1 (SD = 3.9; range 18–30)	Loneliness, anxiety, depression, sensory sensitivities, dislike of crowds, roommate concerns	Note-taker, extended Extended deadlines, extra time for exams, tutor	Peer mentor

Table 1 continued

Study	Location	N	Diagnosis	Gender (M:F)	Age (years)	First hand experiences	Academic supports	Non-academic supports
Madriaga and Goodley (2010)	United Kingdom	8	Asperger's syndrome	5:3	M = 21.1 (SD = 3.9; range 18–30)	Loneliness, anxiety, friendship, depression, marginalization, discrimination	Separate location and extra time for exams	None reported
Mason et al. (2012)	United States	2	Asperger's syndrome	2:0	M = 22.5 (SD = 3.5; range 18–26)	Loneliness, anxiety	None reported	Video modeling, counselor
Oda (2010)	United States	1	Autism spectrum disorder	0:1	Not reported	Anxiety	Tutor	None reported
Pugliese and White (2013)	United States	5	Asperger's syndrome (4), Autism spectrum disorder (1)	5:0	M = 21.27 (SD = 1.88, range 18–23)	None reported	None reported	Cognitive behavioral intervention, problem solving skills lessons
Taylor (2005)	United Kingdom	3	Asperger's syndrome	Not reported	Not reported	None reported	Coursework/ curriculum modifications, notes for classes missed	Counselor, parent involvement
Taylor et al. (2008)	United Kingdom	2	Asperger's syndrome	Not reported	Not reported	Anxiety, disruptive behavior	Coursework/ curriculum modifications (individual alternatives to group assignments), notes for classes missed	Counselor, parent involvement
Van Bergeijk et al. (2008)	United States	1	Autism spectrum disorder	1:0	Not reported	Loneliness, anxiety, depression	Tutor	Peer mentor
Yamamoto and Nihei (2008)	Japan	4	PDD (suspected)	Not reported	Not reported	Loneliness, anxiety, depression, peer relationships, academic failure	None reported	None reported

are described by study in Table 1. Accommodations were described in 9 of 12 articles (75 %) and included extra time on exams (6 of 9, 67 %), lecture notes from instructors (5 of 9, 56 %), use of a separate testing location (3 of 9, 33 %), extended deadlines on assignments (2 of 9, 22 %), lecture notes from peers (2 of 9, 22 %), oral exams (1 of 9, 11 %), and professor facilitation of group projects (1 of 9, 11 %). Course curricula modifications were described in 3 of 12 (25 %) articles (Langford-Von Glahn et al. 2008; Taylor 2005; Taylor et al. 2008) describing individualized supports. In all three cases, the modifications included individual projects in lieu of group projects. In two articles, participants were permitted to give presentations one-on-

one with an instructor rather than in front of a large group (Taylor 2005; Taylor et al. 2008).

Non-academic Supports and Services

Nine of 20 (45 %) studies described non-academic support services provided to college students with ASDs which are shown by study in Table 1. The majority of these supports took the form of peer mentorship programs (5 of 9, 56 %) or assigned counselors, aides, or liaisons (5 of 9, 56 %). Three of 9 (33 %) articles described parental involvement. Single instances of the use of Social Stories (Glennon 2001), disability teams (MacLeod and Green 2009), social

support groups (MacLeod and Green 2009), video modeling (Mason et al. 2012) and cognitive behavioral interventions (Pugliese and White 2013) were also reported.

Discussion

Overall, the major finding of this review is the scarcity of research concerning the experiences of college students with ASD. Only 20 articles describing 69 individuals met the inclusion criteria for this review, which were purposefully broad in order to capture as many articles as possible. Specifically, the current literature base contains fragmented descriptions of programs, experiences, and theoretical suggestions for effective programs. As shown in Fig. 1, the majority of articles ($n = 39$) were excluded because they did not describe firsthand accounts of college experiences, supports, and services. While many of these articles contained suggested practices that are likely to be effective and helpful, it is time to move past theoretical suggestions and into empirically-based recommendations. More research in this area is needed to support effective transition and post-secondary programming. Potential avenues for this research include surveying and interviewing college students with ASD to understand their experiences in post-secondary education in order to inform transitions practices.

A secondary finding of this review involves the research methodologies used in the research literature. Only two studies (Mason et al. 2012; Pugliese and White 2013) contained experimental manipulations; the remaining 18 articles amount to what would be best described as case studies. It should be noted that this review used a liberal definition of a case study as many of the articles provided very brief descriptions of the individual's experiences, presented only one individual as a case study, and the case presented often supported the researcher's theoretical positions on what constituted effective postsecondary programming for individuals with ASD. Of the two experimental studies, both used single subject experimental designs. The first study investigated the effectiveness of video-modeling to improve social communication in college students with ASD (Mason et al. 2012) and the second examined effectiveness of a cognitive-behavioral therapy (specifically a psycho-educational intervention designed to improve problem-solving skills) (Pugliese and White 2013). The effectiveness of these two interventions that are theoretically distinct does not provide any indication of what effective post-secondary programming should entail. In addition, the use of mostly case studies to support theoretical suppositions and two fragmented intervention studies indicate that future research on the experiences of college students with ASD is essential. It is crucial to

investigate the experiences of these students to understand the nature of their reported skill deficits that informs future intervention studies.

These two findings coalesce and support other review studies that the evidence-based supporting practices for adolescence and adults is scant (Volkmar et al. 2014). While the evidence supporting behavioral interventions is overwhelming (Matson 2009; Reichow et al. 2012), it is unclear if these interventions develop the broad and generalized skill sets that are required for competitive employment or postsecondary success. Transporting these interventions from early intervention to transition- and postsecondary-aged youth especially for individuals who are higher-functioning may not be the most effective approach though further research is clearly necessary. Overall, it is unclear which theoretical paradigms would best serve these students when designing programming.

Currently, the K-12 system assumes given the academic achievement of higher-functioning individuals with ASD that they will be successful in postsecondary environments; an assumption that is contraindicated by the literature on their post-school outcomes (Billstedt et al. 2005; Henninger and Taylor 2013). This assumption is also contradicted by the results of this literature review; the majority of the articles included indications of depression, anxiety, and loneliness. Obviously, further research is needed to explore the prevalence rates of these concerns in college students with ASD, but other research has indicated that adolescents with ASD also have reported these issues (Berthoz et al. 2013; Skokauskas and Gallagher 2010; Strang et al. 2012). Beyond the social and emotional difficulties faced by these students, it is also important to understand the areas in which they report that they are academically prepared and the areas academically in which they struggle.

Conclusion

Given the increased prevalence rates of higher-functioning individuals with ASD, it is likely that more individuals with ASD will be entering higher education. This position is supported by the increasing rate of publication on experiences and supports for college students with ASD seen in this review. These articles reported a systematic review of the literature regarding the experiences and support services reported in the peer-reviewed literature for college students with ASD. We found 18 case studies and two experimental intervention studies of individuals with ASD in college. The case studies indicated the presence of anxiety, loneliness, and depression and the need for academic and non-academic supports. One intervention study investigated video-modeling using single-subject methodology; the other intervention study explored a cognitive-

behavior therapy focused on building problem-solving skills. Overall, the current literature-base describing the experiences of and programs for individuals with ASD in college is fragmented and indicates that much research is necessary to understand how to best serve this population and to improve their post-school outcomes.

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