Students with Autism Spectrum Disorder and the Role of Family in Postsecondary Settings: A Systematic Review of the Literature

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Abstract

This article provides a systematic review of the literature pertaining to students with Autism Spectrum Disorder (ASD) and the potential role of family members in higher education settings. The research questions guiding the review included: (a) What is the identified role(s) of family members of postsecondary students with ASD in postsecondary educational settings? and (b) Does family involvement in postsecondary education settings result in positive outcomes for students with ASD? The search terms, *Autism Spectrum Disorder, familial involvement, postsecondary education,* and *educational success* and appropriate synonyms, yielded six articles that fit the inclusion criteria for this review: empirically-based studies conducted in the United States, either dissertations or peer-reviewed articles, published between the years 2003 and 2014, and included some mention of family support or involvement for college students with ASD. Given the very small sample of articles that met the criteria for this review and the limitations of each article, not enough research on family involvement exists to answer the research questions. It is unclear whether or not family members should be involved in postsecondary educational settings, what their potential roles might be, and if family member involvement would be beneficial for students with ASD.

Keywords: Autism Spectrum Disorder, postsecondary education, family involvement, educational success

The Center for Disease Control and Prevention estimated that 1 in 50 children are diagnosed with Autism Spectrum Disorder (ASD) and the prevalence of cases is increasing (Shattuck et al., 2012). Cavanagh and VanBergeijk (2012) reported that approximately 751,000 individuals with ASD in the United States are under age 20 and estimated that 500,000 of these individuals may set their sights on higher education. However, gaining access to postsecondary settings may be a challenge. In a study using the National Longitudinal Transition Study-2 (NLTS-2) data, Shattuck et al. (2012) found that more than 50% of youth with ASD did not participate in postsecondary education within two years after leaving high school and participation rates were lower than for students with learning disabilities and speech and language impairments. Wei, Yu, Shattuck, McCracken, and Blackorby (2012) found that postsecondary students with ASD had the third lowest enrollment rate among 11 disability categories.

Those students with ASD who do move on to postsecondary institutions are at risk for decreased retention and graduation rates (Schlabach, 2008; Wei et al., 2014). Using the NLTS-2 data, Newman et al. (2011) found that approximately 80% of postsecondary students with ASD were working toward some type of diploma, certificate, or license. However, only 39% completed school. While this completion rate is not significantly different from other student disability categories, it is slightly lower than the average graduation rate for all college students. According to the U.S. Department of Education (2013), the average six year graduation rate for first-time college students who started college in 2005 ranged from 31% to 88% depending on the college, with an average graduation rate of 59%. Contrary to reports of being at risk for retention and graduation, though, Wei et al. (2013), who also used the NLTS-2 data, found that community college students with ASD majoring in science, technology, math, or engineering (STEM) were twice as likely to transfer to 4-year universities compared to peers with ASD in non-STEM majors and students with ASD in STEM majors were more likely to persist (i.e., stay in school, graduate) when compared to peers with ASD in non-STEM majors.

Limitations of Postsecondary Students with ASD

In the past, students on the spectrum who have registered with campus disability resource centers (DRCs) typically had diagnoses of ASD, Asperger's Syndrome (AS), Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS), or are described as having "high functioning autism" (Bauer, 2008; Smith 2007). Although campus disability support professionals (DSPs) will continue to meet individuals who might present documentation based on this diagnostic system, the most recently published Diagnostic and Statistical Manual of Mental Disorders (DSM-5) removes the label of AS and PDD-NOS and presents a new definition of ASD. The DSM-5 states that individuals previously diagnosed with AS or PDD-NOS should now be diagnosed with "Autism Spectrum Disorder" (American Psychiatric Association [APA], 2013).

According to the DSM-5, for an individual to qualify for ASD, he or she must have "deficits in social communication and social interaction" as well as "restricted, repetitive patterns of behavior, interests, or activities" (APA, 2013, p. 50). Individuals given the diagnosis of ASD will also be given one of three severity levels ranging from "requiring support" to "requiring very substantial support" (p. 52). The DSM-5 also notes, "Individuals who have marked deficits in social communication, but whose symptoms do not otherwise meet criteria for autism spectrum disorder, should be evaluated for social (pragmatic) communication disorder" (p. 51). Based on the DSM-5 information it seems that college students with ASD may need more support regarding behavioral issues, social communication, and/or social interaction.

Empirical research on the experiences and limitations of college students with ASD is limited (Gelbar, Smith, & Reichow, 2014), but based on the diagnostic criteria in the DSM-5, college students with ASD will most likely experience specific challenges in social communication and interaction. These students may have unwanted social behaviors such as scarce eye contact, appearance of social disengagement or disrespect, verbal interruptions, blinking or talking quickly, excessive nervousness, and/or inappropriate laughter/smiling (Trammel, 2013). These types of behaviors could be judged negatively in a college classroom where unspoken established social norms of engagement, respect, and socializing are often required (Trammel, 2013). Camarena and Sarigiani (2009) documented self-reported social limitations that included understanding others' feelings, expressing feelings, participating in games or activities, and finding peers who share similar interests. Schlabach (2008) also reported that students had difficulty with social relationships as well as challenges with sensory issues, including noise in the classroom environment (e.g. clicking pens) and tactile preferences (e.g., specific bed sheets).

Additionally, researchers have found that postsecondary students with ASD have limitations associated with executive functioning (Adreon & Durocher, 2007). Executive functioning is associated with the area of the brain in charge of problem-solving behaviors (Duncan, 1986) and may include functions such as "forming abstract concepts, having a flexible sequenced plan of action, focusing and sustaining attention and mental effort, rapidly retrieving relevant information, being able to self-monitor and self-correct as a task is performed, and being able to inhibit impulsive responses" (Liss et al., 2001, p. 261). Limitations in executive functioning may manifest as academic issues such as diminished ability to concentrate in class, walk from class to class, work independently, and follow instructions (Camarena & Sarigiani, 2009). Furthermore, case studies have documented the presence of anxiety, loneliness, depression, bullying, roommate concerns, and time management issues among this population (Gelbar et al., 2014). Not all postsecondary students with ASD will have the same level of difficulty with regard to executive functioning, behavioral, and/or social issues; however, these are areas where students may need support while in college.

Purpose of the Review

To assist in serving postsecondary students with ASD and their family members, books have been written specifically for this population to aid with the transition to postsecondary settings. These include publications such as *The Parent's Guide to College for Students on the Autism Spectrum* (Thierfeld Brown, Wolf, King, & Bork, 2012) and *Students with Asperger Syndrome: A Guide for College Personnel* (Wolf, Thierfeld Brown, & Bork, 2009). The authors of these books contend that parental or family involvement during the transition to a postsecondary environment is often essential for student success (Wolf et al., 2009) and that communication between university professionals, specifically DSPs and family members, should be ongoing (Thierfeld Brown et al., 2009). Specifically, the authors recommend family involvement during the transition to college in order to help answer DSPs questions and gauge a student's level of self-advocacy skills, his/her knowledge of ASD diagnosis, specific reactions to stress/changes, level of independent living skills (e.g., laundry, shopping), employment history, and/or supervision needs (Wolf et al., 2009). Wolf et al. reason that, given some of the communication deficits among this population, involving family members can help expedite the process of identifying students' needs as well as (a) actively involve the student, (b) make the family feel supported and understood, and subsequently (c) the DSP does not become overwhelmed with the small details (p. 32).

While the authors do promote student independence and self-advocacy, Wolf et al. (2009) recommend DSPs stay in touch with parents after the initial transition. For example, a DSP "point person" would have regular contact with family members regarding a student's progress. After the student provides written permission, the point person would establish agreed upon boundaries with parents or other family members and determine how often is appropriate to discuss the student's progress. With the parent now moving to a "consulting" role, a phone call schedule of once per week for five minutes and no more than two emails per week may be established to discuss a student's progress (Wolf et al., 2009). The authors reported that on-going communication gives parents an opportunity to provide information they feel might be helpful and the DSP can provide an update on the student's general progress during the semester. However, routine non-emergency situations would not be regularly communicated by DSPs to family members, such as missed appointments or classroom assignments (Wolf et al., 2009).

Thierfeld Brown et al. (2012) and Wolf et al. (2009) have recommended that ongoing family involvement (e.g., parents) throughout the college experience is needed and can lead to student success. They suggest that adding additional familial supports may help with retention and graduation rates of students with ASD through addressing some of the limitations that postsecondary students with ASD experience. However, it is imperative to ground recommendations on current empirically based research to ensure that best practices are used. Therefore, the purpose of the current article is to provide a systematic review of the literature on students with ASD and family involvement during college experiences. If parents or other family members are to have significant roles in postsecondary educational environments, it will be important for DSPs to be informed of these specific roles and exactly how family members can help support college students with ASD.

Research questions about family involvement. Specific research questions were developed to help guide the authors of the manuscript. The research questions included:

1. What is the identified role(s) of family members of postsecondary students with ASD in postsecondary educational settings?
2. Does family involvement in postsecondary education settings result in positive outcomes for students with ASD?

The authors chose to use the term "family" to incorporate research that may have included other family members besides parents.

Methodology

Using the research questions, the authors identified four search concepts: ASD, familial involvement, postsecondary education, and educational success. The authors conducted electronic searches in the following five indexes/databases in the Northern Illinois University library system: CINAHL (EBSCO), ERIC (EBSCO), PsychInfo, Web of Science, and Proquest Dissertations. Using these databases, synonyms were harvested for each concept. Harvested synonyms for each individual concept were combined with Boolean operator OR, all four concept lists were combined using Boolean operator AND (See Appendices A & B), and searches were run in CINAHL, ERIC, and Web of Science databases in March and April of 2014. The same terms were used to search in ProQuest dissertations in everything (title, abstracts, keywords) except full text. Similar search terms, though differently constructed, were used to search PsychInfo. The authors found that using all four concepts provided too few results. The authors then repeated the searches, excluding the educational success concept. Results then were limited by date (i.e., 2003-2014) and peer-review (except in the ProQuest dissertation database). All of the authors reviewed the entire results list and chose appropriate articles to review further. Once the database searching was complete, the authors examined reference lists of articles and dissertations. In addition, authors hand searched the table of contents of ten journals for the last ten years (See Appendix C).

Results

Result lists with titles and abstracts for each database were reviewed. Only empirical studies within the United States conducted between 2003 and 2014 were included; review articles were excluded. In all, 459 records were reviewed from databases (42 titles reviewed using all four concepts (column 3) added to the 417 titles resulting from searching with three concepts (See Table 1). Six articles were deemed appropriate for this review article. Searching the table of contents of ten journals for ten years revealed no additional titles.

The authors found six empirically-based, peer reviewed articles that were related to the research questions outlined above. A description of the findings of each article is provided below and Table 2 provides an outlined summary of each article.

Barnhill (2014) conducted an exploratory study of current practices for supporting students with ASD on college campuses. Participants (*N* = 30) included representatives from campus DRC offices at 19 public institutions and 11 private institutions that offered services for students with ASD such as extra time on exams, an alternate testing site, tutoring, and a note taker. Respondents participated in a telephone survey consisting of open and closed response items. The sections of the survey identified demographic information, offered support services, student outcome information, and the extent of parental involvement. Although most DRC representatives did not have student outcome information (e.g., graduation rates, drop-out rates), at least one respondent reported that students with ASD who lived within two hours of the university fared better in school than students who lived further away.

DRC representatives indicated that parents could be a positive resource and could offer important information about their child with AS or ASD. Barnhill (2014) reported that DRC professionals viewed parents positively, as partners, and encouraged a relationship with parents by asking students with ASD to sign an informed consent form so they could speak with each other. Not all DRC personnel involved parents to the same extent. One respondent communicated with parents via weekly emails that eventually tapered off to twice per month and then once per month. Another respondent reported that students with ASD were assigned peer mentors and together both individuals called the student's parents once per week. Other activities that respondents reported included parent information sessions in the summer or beginning of the semester, written reports (on progress, strengths, areas of concern) sent to parents after a summer transition program, group parental meetings twice a semester, and end-of-semester celebrations with family members. Reported limitations of this study were that an Internet search was used to identify programs and not all programs targeted in the study offered support services specifically for students with ASD. Other programs that did offer services were not contacted; therefore, some programs that may have been appropriate for the study were not included.

Camarena and Sarigiani (2009) interviewed high functioning students with ASD (*n* = 21) and their mothers (*n* = 20) and fathers (*n* = 13) to assess postsecondary educational aspirations, perceived obstacles, and resources needed for success. Participants who volunteered for the study were recruited via email using special education networks in Michigan. Interviews

Table 1

Databases Used for the Systematic Review

Database	Date	Search with 4 Concepts	Search with 3 Concepts
CINAHL	4/9/2014	6 (4)	71 (53)
ERIC	3/28/2014	39 (14)	714 (179)
Proquest Dissertations	4/20/2014	1 (1)	22 (21)
PsychInfo	4/9/2014	14 (14)	44 (10)
Web of Science	4/2/2014	9 (9)	178 (154)
TOTALS	4/30/2014	69 (42)	1,029 (417)

Note. Numbers in parentheses refer to results once peer-reviewed and date limitations were applied to databases.

took place in-person with the survey consisting of a demographics section, Likert-scale rating questions, and open-ended questions. Qualitative data were analyzed using a constant comparative method and themes were established. One question on the survey asked of both parents and students was, "Do you have any other ideas for what would help students with the same kinds of special needs as you ('your child' was used for parents) be more successful in preparing for college?" (p. 123). Two categories of support program recommendations were established that included academic (i.e., academic accommodations, coursework/curriculum) and *nonacademic* supports. The content analysis for the question above found a theme of *parental involvement* that fell within nonacademic supports. Examples of other nonacademic support themes included social skills/peers/mentoring, housing/roommate concerns, trained specialists/aides, and campus disability awareness. Parental involvement was mentioned by four of the mothers (20%) in the study. No students or fathers expressed a need for parental involvement when asked about specific program recommendations. The authors did not detail what was meant by parental involvement as a nonacademic support.

Limitations that the authors noted included a small sample size, documentation was not required to prove an ASD diagnosis, and a comparison group of students without disabilities was not included. It should be noted that parents and students were more concerned with nonacademic situations (e.g., daily living skills, housing, campus life transition) rather than academic success and parents were concerned that they would have to "educate" postsecondary institutions about ASD and student needs.

Morrison, Sansosti, and Hadley (2009) interviewed mothers (*N* = 4) of college-bound male students with ASD on supports or accommodations and self-advocacy skills or strategies needed to be successful in school. Parents were recruited through a professional network and asked open-ended questions regarding college supports or accommodations and self-advocacy skills or strategies needed to increase chances of student success in school. Two authors reviewed the transcripts and identified two primary themes (i.e., supports and accommodations, self-advocacy needs and supports). Morrison et al. (2009) identified a sub-theme of parental involvement related to the larger theme of self-advocacy needs and supports. The authors reported that all mothers agreed that parental involvement would be needed more for their children compared to their peers. Parental involvement activities included assistance in daily living activities (e.g., laundry, money managing, doctor appointments, paying bills). One parent reported a need to allow her son to gain independence, but also to keep a "watchful eye for potential struggles" (p. 83). Mothers identified their role as helping their children identify and deal with challenging social situations, such as problems that arise in a residence hall or being able to identify if someone is trying to take advantage of them. Reported limitations of the study included a small sample size and the use of only qualitative interview data.

Robledo and Donnellan (2008) interviewed academically successful college students with Autism (*N* = 5; two females and three males). The purpose of the study was to explore supportive relationships that students had with others. The authors reasoned that supportive relationships have a significant and positive impact on the lives of students with ASD in college. Participants were asked to identify supportive relationships, describe the relationships, and the role of communication in relationships. Ten of the individuals identified were paid support staff (59%) and seven were parents (41%), while 15 out of 17 (88%) individuals identified were female. Out of the parents identified, five were mothers, while one was a father and the other a stepfather. Using constant comparative analysis, six themes of supportive relationships emerged from the data: *Trust, Intimate Connection, Shared Vision of Independence, Presumption of Competence, Understanding,* and *Communication.*

Trust was reported as foundational to supportive relationships while Intimate Connection was described as respect for one another, a closeness or bond, and determined the overall quality of the relationship. Shared Vision of Independence was something that participants felt must be a goal, acknowledged and supported by both individuals in the supportive relationship. A Presumption of Competence was described as the desire to be treated like a "regular" person, while Understanding was described as supportive individuals being knowledgeable of the student's skills as well as the impact of ASD. Lastly, Communication was described as a challenge for students and an area where supporters may be most helpful. Limitations to the study included a small sample size and that all participants were white and from a middle-class background. Furthermore, some participants needed a support person present, limiting the privacy of the interviews.

Schlabach (2008) interviewed postsecondary students with AS (*N* = 5; four males and one female) and DSPs (*N* = 4) to explore the college experience of students with AS as perceived by students themselves and their service providers. Three postsecondary institutions were targeted (i.e., a 2-year community college, private liberal arts university, large public university) for the study and DSPs were contacted at each institution and asked to participate. The DSP participants were then asked to recruit potential student participants with AS. Qualitative interview data were analyzed using cross-case analysis as well as comparative analysis. After analyzing student interviews, a major theme of *Students Rely on External Supports to Navigate the College Experience* was noted. A *Role of Family Members* sub-theme was noted as an external support according to the student participant data. The author noted that all the student participants lived at or near their home so that family members could provide emotional support. Family members helped students choose an institution to enroll in, joined students on their first visit, helped students with time management, and served as advocates.

Data analysis of the interviews with DSPs determined a major theme of *Involvement* and *Support of the Parents Facilitates Success for Students with AS.* Parents were viewed as providing good insight on supporting students in and out of the classroom. DSPs viewed parents living near the students as a positive factor that provided students with an environment where sensory issues (e.g., noise, sleep issues) could be minimized. DSPs also viewed parents as social interpreters or coaches when dealing with communication issues that could arise on campus. In one case, a male student relied on his mother to disclose his disability to faculty members. Schlabach also pointed out that students and DSPs both cautioned about the extent of parental involvement due to the need for students to become increasingly independent. Limitations of the study included a small sample size, a qualitative only study design, and researcher bias when analyzing qualitative data and reporting the results.

Szentmiklosi (2009) interviewed community college students with AS (N = 5; three males and two females) to understand how the students utilized self-determination during their college experience. Self-determination was described as a set of skills in which students are goal oriented, aware of strengths and limitations, and capable of self-regulated, autonomous behavior (Field et al., 1998 as cited in Szentmiklosi, 2009). Participants were recruited through the campus DRC via staff assistance. The author reported that levels of self-determination were different among the participants, but five major and two minor themes were reported. Major themes included: *Participants Enjoyed Academic Success, Found Disability Services and Accommodations Important, Chose Majors Based on Personal Interests, Relied on Family Members for Support,* and *Had Difficulty Developing Social Connections on Campus.* Minor themes included: *Importance of Faculty Connections* and *Importance of Attendance at a Community College Prior to a University*. One of the major themes pertaining to this report is that participants *relied on family members for support and influence*. The author further explained that participants reported that their parents heavily influenced the choice of postsecondary institution, managed disability records and information, attended multiple DRC appointments, acted as class note taker (i.e., one mother), and provided transportation. All of the participants in the research study lived at home with their families. Limitations of the study included a small sample size, expressive communication difficulty among participants, and potential researcher bias when analyzing the data and reporting the results.

Discussion

Only six articles met the criteria established for the current systematic review. Each of them were empirically-based studies conducted in the United States, either dissertations or peer-reviewed articles, published between the years 2003 and 2014, and included some mention of family support or involvement for college students with ASD. Given the very small sample of articles that met the criteria for this review, in addition to the limitations that each article possessed, not enough research on family involvement exists to clearly answer the research questions outlined in this manuscript.

Each of the articles described in this systematic review contained limitations within their methodologies such as small sample sizes, lack of experimental designs with a control group, the majority of family members were identified as mothers, the types of participants varied (e.g., students, parents, DRC staff), various levels of ASD diagnoses were included in the studies (ASD vs. AS), and in some instances there were communication difficulties among participants with ASD. Due to these limitations and lack of strong empirical evidence, recommendations that any of these authors have provided on family involvement should be considered more theoretical in nature. Therefore, more empirically sound research is needed in order to inform DRC professionals about potential family members' roles and their impact on students.

As described earlier, book authors (Thierfeld Brown et al., 2012; Wolf et al., 2009) have recommended family involvement in postsecondary settings to support students with ASD. Similarly, some of the articles identified in this systematic review have identified parental involvement in postsecondary settings as important. However, it appears premature to provide

Table 2

Description of Literature Focused on Postsecondary Students with ASD and Family Members (e.g., parents)

Authors (Year)	Participants	Primary Diagnosis Noted	Methodology	Summary of Findings
Barnhill, 2014	DRC Staff (*N* = 30)	AS High Functioning Autism (HFA)	A mixed methods exploratory study of current support practices among higher education institutions that serve students with ASD. A telephone survey was utilized with open and closed response items. Data gathered included: Support services offered (with description), Student outcomes, Extent of Parent Involvement	A theme included the importance of including parents. Parents were viewed positively and as partners in programs. Amount of parental involvement varied greatly among institutions, however. Examples of involvement included weekly e-mails, parental information sessions, and written progress reports to parents.
Camarena & Sarigiani, 2009	Students with ASD (*n* = 21) Mothers (*n* = 20) Fathers (*n* = 13)	ASD	A mixed-methods study to assess postsecondary aspirations, potential obstacles, and resources needed for success. Semi-structured interviews were completed with adolescents with high functioning ASD and their parents. Likert-scale response items were also used.	A theme of parental involvement was found and categorized as a nonacademic support. This theme was found in the responses of mothers (n=4) when asked about recommendations for University programs. The authors did not define or provide examples of the parental involvement theme.
Morrison, Sansosti, & Hadley, 2009	Mothers of college bound students with AS (*N* = 4)	AS	A qualitative study using an open response interview format to assess perceived college supports, accommodations, and student self-advocacy skills needed to be successful.	A sub-theme of parental involvement was found, related to a larger theme of self-advocacy needs and supports. Examples of parental involvement included assistance with laundry, managing money, paying bills, managing appointments, and identifying and dealing with challenging social situations.
Robledo & Donnellan, 2008	College students with Autism (*N* = 5)	ASD	A qualitative study using semi-structured interviews to explore supportive relationships that students had with others. Participants were asked to define supportive relationships, identify specific individuals, describe ways in which relationships were supportive, and the role of communication.	Participants identified 17 individuals total (7 parents, 10 paid support staff) (15 out of 17 female). Six themes emerged from the data: Trust, Intimate Connection, Shared Vision of Independence, Presumption of Competence, Understanding, and Communication.

(Table 2, Continued)

Schlabach, 2008	Students with AS (*N* = 5) DRC Staff (*N* = 4)	AS	A qualitative study using semi-structured interviews to explore the college experience of students with AS as perceived by students and their service providers.	Family member involvement was a theme identified through both student and staff interviews. Students relied on family members for emotional support and lived at or near the family home. Family members, usually parents, assisted with choosing an institution and visiting campus, time management, served as advocates, and assisted with social coaching/ communication issues.
Szentmiklosi, 2009	Community college students with AS (*N* = 5)	AS	A qualitative study using semi-structured interviews to assess levels of participants' self-determination during college.	Relied on family members for support and influence was a major theme. Parent roles included managing disability information, attending multiple disability service appointments, acting as class note taker, and transportation.

answers to the current research questions based on the articles reviewed in this systematic review. The first research question was related to family members' roles after student enrollment. While the articles reviewed mentioned family members' involvement being important (Barnhill, 2014; Robledo & Donnellan, 2008; Schlabach, 2008), more non-academic in nature (e.g., daily living skills) (Camarena & Sarigiani, 2009; Morrison et al., 2009; Schlabach, 2008), and decreasing as students learn to self-advocate (Barnhill, 2014; Robledo & Donnellan, 2008; Schlabach, 2008), research studies should be conducted to concretely identify specific family member roles in either academic and/or nonacademic categories. Furthermore, one article (Barnhill, 2014) discussed family involvement varying widely depending upon the postsecondary institution. This suggests that standard roles have not yet been identified and brings into question whether or not family members' involvement is needed or desired at the postsecondary level.

None of the reviewed articles provided outcome data on students with ASD related to family involvement. Therefore the authors were unable to answer the second research question. While one study (Barnhill, 2014) attempted to gather student outcome data, the author did not link this to family involvement and found that many DRC offices did not track student outcome data. Although family involvement is reported to be beneficial, it would imperative to measure the effects of family involvement through objective outcome data such as grade point averages, retention, and graduation rates. It is unclear whether or not family members should be involved in postsecondary educational settings, what potential roles would be, or if family member involvement would be beneficial for students with ASD. Therefore the authors recommend research be conducted that is targeted at all stakeholders (i.e., DRC staff, family members, students, faculty).

Future Research

New research on this topic should include a needs assessment, utilizing postsecondary students with ASD, to ascertain their need or desire for family member involvement while enrolled in school. Including students first is consistent with the "Nothing About Us, Without Us" (Jorgensen, Bates, Frechette, Sonnenmeier, & Curtin, 2011) belief that individuals with disabilities should be directly involved with issues pertaining to them. If students perceived a need or are open to the idea of family member involvement, additional information from family members themselves would be helpful to gauge their desire to assist students and potential roles they might fill. Finally, the authors recommend a study utilizing DRC staff participants to assess the appropriateness or need for family involvement, staff perceptions of family member involvement, potential roles family members may fulfill, the extent or intensity of family involvement, and outcomes for students with ASD. Although some have indicated the importance of family involvement, evidence in the literature is unclear about family roles, the intensity of family members' involvement, and its impact on students' self-sufficiency and postsecondary outcomes. Research data gathered from all postsecondary stakeholders could help answer the research questions outlined in this article.

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Appendix A

Concept	Concept List
Autism	Autism OR "Asperger's syndrome" OR "autism spectrum disorder" OR Asperger* OR "child developmental disorders, pervasive" OR "pervasive developmental disorder*" OR "communication disorders" OR "learning disorders" OR "developmental disabilities" OR "autistic disorder"
Postsecondary Education	“junior college” OR "post secondary education" OR "post-secondary education" OR "higher education" OR college* OR "postsecondary education" OR "college applicants" OR "college choice" OR "college readiness" OR "community college" OR "technical college" OR "transition to adulthood" OR university* OR "college students" OR "transitional programs" OR "college acceptance" OR college
Familial Involvement	“parental involvement” OR "parental advocacy" OR "family involvement" OR "family advocacy" OR "advocacy" OR "family school relation" OR "parent school relations" OR "family role" OR "parents as teachers" OR "parent student relationship" OR "parenting skills" OR "parent responsibility" OR "parent teaching" OR parent OR family
Educational Success	“school success” OR "school failure" OR retention OR graduation OR dropout OR "dropout rates" OR "graduation rates" OR "student dropouts" OR "School Holding Power" OR "Academic Persistence" OR "Attendance" OR "College Attendance" OR "Dropout Research" OR "Dropouts" OR "Student Attrition" OR "Withdrawal (Education)" OR "Academic Failure" OR "College Readiness" OR "Excellence in Education" OR "Academic Achievement" OR "Graduation" OR "Educational Attainment" OR "Graduation Rate"

Appendix B

Search with four terms:
(Autism OR "Asperger's syndrome" OR "autism spectrum disorder" OR Asperger* OR "child developmental disorders, pervasive" OR "pervasive developmental disorder*" OR "communication disorders" OR "learning disorders" OR "developmental disabilities" OR "autistic disorder") AND (“junior college” OR "post secondary education" OR "post-secondary education" OR "higher education" OR college* OR "postsecondary education" OR "college applicants" OR "college choice" OR "college readiness" OR "community college" OR "technical college" OR "transition to adulthood" OR university* OR "college students" OR "transitional programs" OR "college acceptance" OR college)) AND (“parental involvement” OR "parental advocacy" OR "family involvement" OR "family advocacy" OR "advocacy" OR "family school relation" OR "parent school relations" OR "family role" OR "parents as teachers" OR "parent student relationship" OR "parenting skills" OR "parent responsibility" OR "parent teaching" OR parent OR family) AND (“school success” OR "school failure" OR retention OR graduation OR dropout OR "dropout rates" OR "graduation rates" OR "student dropouts" OR "School Holding Power" OR "Academic Persistence" OR "Attendance" OR "College Attendance" OR "Dropout Research" OR "Dropouts" OR "Student Attrition" OR "Withdrawal (Education)" OR "Academic Failure" OR "College Readiness" OR "Excellence in Education" OR "Academic Achievement" OR "Graduation" OR "Educational Attainment" OR "Graduation Rate")

Search with three terms:
(Autism OR "Asperger's syndrome" OR "autism spectrum disorder" OR Asperger* OR "child developmental disorders, pervasive" OR "pervasive developmental disorder*" OR "communication disorders" OR "learning disorders" OR "developmental disabilities" OR "autistic disorder") AND (“junior college” OR "post secondary education" OR "post-secondary education" OR "higher education" OR college* OR "postsecondary education" OR "college applicants" OR "college choice" OR "college readiness" OR "community college" OR "technical college" OR "transition to adulthood" OR university* OR "college students" OR "transitional programs" OR "college acceptance" OR college)) AND (“parental involvement” OR "parental advocacy" OR "family involvement" OR "family advocacy" OR "advocacy" OR "family school relation" OR "parent school relations" OR "family role" OR "parents as teachers" OR "parent student relationship" OR "parenting skills" OR "parent responsibility" OR "parent teaching" OR parent OR family)

Appendix C

Journal titles

Autism
College Student Journal
Disability and Society
Education and Training in Autism and Developmental Disabilities
Focus on Autism and other Developmental Disabilities
Journal of Autism and Developmental Disorders
Journal of College Student Retention
Journal of Intellectual and Developmental Disability
Journal of Postsecondary Education and Disability
Teaching Exceptional Children