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## How Involved Should They Be? Students with ASD in Postsecondary Settings and Their Family Members

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### Abstract

We investigated the need for family member involvement for students with Autism Spectrum Disorder (ASD) in postsecondary settings. We also looked at the perceived needed and fulfilled roles of family members and if family member involvement resulted in positive outcomes for postsecondary students with ASD. We surveyed 211 postsecondary Disability Support Professionals (DSPs) through the AHEAD organization. Using a mixed methods approach including inductive content analysis, results primarily indicated that there is a need for family members to be involved non-academically with students with ASD. We discuss roles that DSPs think family members should fulfill versus roles that DSPs think that family members are actually fulfilling. It is apparent that DSPs think family member involvement is important but must be balanced with increasing the independence of students with ASD while enrolled in school.

### Keywords

Family Involvement, Higher Education, Disability Support Professionals, Autism Spectrum Disorder, Academic Accommodations, Mixed Methods

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## How Involved Should They Be? Students with ASD in Postsecondary Settings and Their Family Members

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An increasing number of students with Autism Spectrum Disorder (ASD) have been pursuing postsecondary education in recent years (Cavanagh & VanBergeijk, 2012), which has led to a rise of documented experiences of college students with ASD (Adreon & Durocher, 2007; Camarena & Sarigiani, 2009; Gelbar, Smith, & Reichow, 2014; Schlabach, 2008; Trammell, 2013). This population of students often arrive on campuses dealing with deficits related to communication, social interaction (American Psychiatric Association, 2013; Longtin, 2014), and atypical behaviors (Trammell, 2013). Additionally, researchers have described deficits associated with problem-solving behaviors (e.g., working independently, concentrating in-class) associated with executive functioning areas of the brain (Adreon & Durocher, 2007; Camarena & Sarigiani, 2009; Longtin, 2014). Family members of students with ASD are often important in the decision-making process during the transition from high school to postsecondary education (Chiang, Cheung, Hickson, Xiang, & Tsai, 2012).

Postsecondary students with ASD are often eligible for free, reasonable academic accommodations and support based upon their diagnosis. The majority of postsecondary institutions in the U.S. have one or more disability support professionals (DSPs) who work with students with disabilities who are enrolled in courses. DSPs typically work in campus offices often titled as Disability Resource Centers (DRCs) or Disability Support Services (DSS). These professionals often have titles including Director, Coordinator, Counselor, Advisor, or Americans with Disabilities Act (ADA) Coordinator, among others. Individual DSPs may serve all students with disabilities on a campus or specific populations depending upon their education and professional experience. (e.g., Sign Language Interpreter). Common accommodations sought by students with ASD include exam accommodations, note taking assistance, ongoing “check-in” meetings with DSPs, organizational/time management counseling, tutors, private on-campus living quarters, and assistance communicating with faculty members. While DSPs can help accommodate most academic concerns, they are not necessarily equipped or required to assist with social or behavioral supports, or with deficits related to students’ executive functioning.

Due to the unique social needs of college students with ASD, some authors and researchers have recommended family member involvement through the transition period from secondary to postsecondary environments, and even weeks or months after enrollment (Thierfeld Brown, Wolf, King, & Bork, 2012; Wolf, Thierfeld Brown, & Bork, 2009). However, social expectations and legislation often dictate that all students act independently once enrolled in college.

### **Secondary and Postsecondary Disability Legislation**

It is important for all postsecondary stakeholders (e.g., parents, students, DSPs) to understand the legislative differences in serving students with ASD in kindergarten through 12<sup>th</sup> grade (K-12) and postsecondary settings. Thierfeld Brown et al. (2012) reported that many families do not understand differences in the laws. Therefore, DSPs must be able to explain these differences to incoming students and their family members. The following sub-sections will include a discussion of the (IDEA) of 2004 and Section 504 of Rehabilitation Act of 1973, which apply to K-12 settings. Section 504 also applies to postsecondary settings along with the Americans with Disabilities Act Amendments Act of 2008 (ADAAA).

#### **IDEA and Section 504 Plans**

Students who are identified as having ASD in K-12 school districts have a right to special education services as mandated by the Individuals with Disabilities Education Act (IDEA) of 2004. The law applies to children with disabilities from birth through high school graduation or 21 years of age (see [idea.ed.gov](http://idea.ed.gov); Thierfeld Brown et al., 2012). The purpose of the law is to provide a “free appropriate public education” (FAPE) to help children with disabilities prepare for life after high school (Smith & Bales, 2010). The responsibility is on school districts to identify and serve students with disabilities. Under the IDEA, Individualized Education Programs (IEPs) are developed with a team that often includes students, family members, special educators, and other appropriate individuals (e.g., psychologists) for students with academic difficulties. Family members are involved in the IEP process because they are seen as key informants and participants in the process. Furthermore, the IDEA specifically states *family involvement* is important for student success (Shogren & Plotner, 2012). Each student’s IEP outlines specific needed accommodations, learning goals, and long-term transition goals such as plans for higher education or employment. Even though family member involvement is seen as important in K-12 settings, this rationale changes once students exit high school.

#### **ADAAA and Section 504**

Whereas the IDEA is focused on student *success* in K-12 years, in postsecondary environments the focus of disability legislation is on *equal access*. The purpose of Section 504 of the Rehabilitation Act of 1973 and the Americans with Disabilities Act Amendments Act of 2008 (ADAAA) in higher education settings is to protect individuals’ civil rights by prohibiting discrimination based upon disability (American with Disabilities Act, 42 U.S.C. § 12132; Rehabilitation Act, 29 U.S.C. § 794). Students must not be denied enrollment based upon disability and, once enrolled, must be provided access to all programs and services through the use of free, reasonable accommodations. Students must self-identify to DRCs and request specific accommodations (e.g., note taker, assistive technology, single-room housing). Although IDEA laws do not apply in postsecondary settings, DSPs can use documentation

(e.g., IEP, Section 504 plan) from a student's K-12 years, often in addition to other documentation (e.g., proof of ACT test accommodations), to help establish services in college.

Equal access does not guarantee success in postsecondary environments and the law differs from K-12 settings in that students are required to self-identify and seek out needed services independently in postsecondary environments. Furthermore, students are required to notify DSPs if an accommodation was not effective (e.g., a volunteer note taker quits) (Simon, 2011). Due to deficits related to communication and executive functioning, this may prove difficult for some students with ASD to accomplish without help from family members or other support professionals.

While parents are often highly valued and included in the determination of accommodations and services during the K-12 years, students are more or less expected to act independently and advocate for themselves once they reach postsecondary institutions. Another key difference between secondary and postsecondary settings is parents' access to students' records. Parents have access to information regarding their children in K-12 settings, but academic information becomes private in postsecondary settings unless Family Educational Rights and Privacy Act (FERPA) rights are waived by the student (Dente & Coles, 2012; Hewitt, 2011). Informational books have been written specifically for this population to assist with the transition to postsecondary settings such as, *The Parent's Guide to College for Students on the Autism Spectrum* (Thierfeld Brown et al., 2012) and *Students with Asperger Syndrome: A Guide for College Personnel* (Wolf et al., 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 DSPs and family members should be ongoing (Thierfeld Brown et al., 2012). However, specific roles family members should fulfill in postsecondary environments is unclear.

### **Research on Family Member Involvement**

Dallas, Ramisch, and McGowan (2015) conducted a systematic review of the literature on family member involvement of students with ASD in postsecondary settings that elicited six empirically-based research articles. The results of the review suggested that very little research has been conducted on this topic and family member roles are not clearly defined after students enroll in college. Results also suggested that family member involvement at the postsecondary level is important, more non-academic in nature, and generally decreases as students learn to self-advocate (Dallas et al., 2015). However, it is not clear that family member involvement contributes to positive academic outcomes (e.g., retention, graduation) among college students with ASD.

Morrison, Sansosti, and Hadley, (2009) outlined some family member roles that included: assistance with daily activities such as laundry, managing money, bills and medical appointments. Mothers in this study self-identified their roles as assisting with social challenges their college children with ASD may face. Szentmiklosi (2009) detailed family member roles that included: parents influencing choice of college, dealing with disability records, attending meetings with the DRC, being a note taker for the student, and providing transportation. In another study, DSPs reported family members facilitating success by giving good insights, being social/communication coaches, and living near students (Schlabach, 2008). Barnhill (2016) reported that family member involvement varied greatly among institutions and reported that DSPs sometimes provided the following to family members: weekly e-mails, written progress reports, facilitated informational sessions.

Interestingly, Schindler, Cajiga, Aaronson, and Salas (2015) found that study participants ( $N = 11$ ), who were first-year college students with ASD involved in a mentoring

program, reported parent involvement as being either supportive or overbearing. Parental help with homework and decisions made on the students' behalf were viewed as negatively affecting progress toward academic and self-advocacy skills. Therefore, results suggested that over-involvement of family members may be detrimental to student outcomes (Schindler et al., 2015).

Zeedyk, Tipton, and Blacher (2014) called on more research aimed at postsecondary students with ASD regarding the areas of living supports, practical and social skills, as well as educational accommodations. Dallas et al. (2015) also recommended more research and noted that previous research on college students with ASD and family members has been limited by small sample sizes ( $N$  range = 4-30) and inconsistent guidance on appropriate family member roles.

### **Purpose of the Study**

The purpose of the current study was to examine postsecondary DSPs' perceptions regarding the need for family involvement of students with ASD, and what specific roles family members might fulfill. DSPs were chosen for the study due to their contact with both students and family members.

Research questions that helped guide the study included:

1. What is the need for family involvement of students with ASD at the postsecondary level?
2. What are the perceived needed and fulfilled roles for family members of students with ASD in postsecondary settings?
3. Does family member involvement result in positive outcomes for students with ASD?

### **Authors' Introduction**

#### **Bryan Dallas, Ph.D., CRC, LCPC**

Since the late 1990's I have worked with postsecondary students with disabilities to ensure they have access to programs and services in college settings. This ensures students with disabilities have a level playing field when pursuing their goals in higher education. I now train graduate rehabilitation counseling students on how to work with adults with disabilities pursuing higher education and employment goals. Students with ASD are increasingly seeking support services in higher education, but best practices are lacking in how best to serve this population. I am interested in providing postsecondary disability service providers more information about this population and establish best practices through research. I believe we have contributed to the field through conducting the current study and I intend to distribute the results to postsecondary disability support providers. Additionally, I believe further research is needed on this topic including other postsecondary stakeholder groups.

#### **Julie Ramisch, Ph.D., LMFT**

I have always been interested in helping families with children with disabilities stay connected and better navigate resources and their communities. I have spent my research career learning about families with children with disabilities, specifically families with children with autism. After earning my Ph.D. I worked in an academic setting conducting research and teaching students how to become marriage and family therapists. I also have a private practice

where I help individuals, couples, families, and children. For this research project, my goal was to integrate my knowledge of families with children with autism with our interest in learning more about the postsecondary experience. Generally, I believe that families do better when they work together, but I think that there needs to be more information and guidance for families about what to do after their child transitions from the structured setting of high school.

### **Alyssa Ashmore**

My work with individuals with disabilities and diagnoses began in 2013 at a special recreation center, and my passion for this field of work has evolved from a part-time job to an aspiring career. Currently, I am an undergraduate Communicative Disorders student about to begin graduate school in pursuit of becoming a speech-language pathologist. As a future clinician, I will undoubtedly encounter clients with ASD and their families. Through my own anecdotal experiences as well as my studies, I have grown to value the significance of family involvement for developing individuals with disabilities. Whether in therapy, K-12, or college, I believe the involvement of family members has a critical influence on outcomes. This study helps define appropriate family involvement for postsecondary students with ASD that can be used as a guideline by disability support professionals; it can also be a steppingstone for further research on family involvement for other postsecondary populations with disabilities.

## **Methods**

### **Participants**

Participants for the study included postsecondary DSPs who were members of the Association on Higher Education and Disability (AHEAD). We obtained human subjects approval from the Institutional Review Board at Northern Illinois University prior to conducting the study. AHEAD members ( $N = 2,764$ ) were e-mailed and asked to participate in the study. Eligible participants must have had knowledge of and current experience working with college students with ASD. Two hundred and sixty-eight DSPs responded to the survey, and 211 completed the entire survey, indicating a 79% survey completion rate and an overall response rate of 7.6%.

### **Instrument**

We constructed a quantitative and qualitative survey based on a systematic review of the literature (Dallas et al., 2015) regarding college students with ASD and family involvement, as well as a 2015 pilot study that included qualitative interviews with DSPs from 10 community colleges in the Midwest. The purpose of the pilot study was to identify common roles that family members of students with ASD fulfill after students are enrolled in college. We compared pilot study data to data found in the literature in order to create survey items for the current study. The survey used for the current study consisted of 22 items related to the research questions and DSP demographic information. We asked DSPs if family members should be involved academically (e.g., note taker, tutor) and non-academically (e.g., budgeting, laundry), as well as roles DSPs thought family members *should* fulfill and roles family members are most likely to *actually* fulfill related to their student with ASD. Roles were identified with check boxes and participants could choose to select one or more roles based on their experiences with family members. Additionally, we asked DSPs to rate their experiences (i.e., positive vs. negative) working with family members of students with ASD. For many items we asked DSPs to explain their answer by typing a more detailed response.

## Data Collection Procedures

AHEAD then e-mailed their members and requested that they participate in the study by completing the electronic Qualtrics-based (Qualtrics, 2016) survey. A link to the survey was provided to individuals who received the e-mail. An e-mail reminder was sent to AHEAD members two weeks after the initial e-mail. A final e-mail reminder was sent two weeks after the second e-mail attempt.

## Data Analysis

We exported quantitative and qualitative survey results from Qualtrics (2016) to SPSS (IBM SPSS) statistical software and Microsoft Word, respectively, for further analysis. We analyzed qualitative data using inductive content analysis (Elo & Kyngäs, 2008). Content analysis is an efficient way to conduct analysis on written statements and communication to enhance understanding of a topic. In order to qualitatively analyze survey questions with text responses, we independently used open coding techniques to identify meaningful statements for each question. Next, we separately identified categories and sub-categories from meaningful statements using content-characteristic words. We then met to complete the final abstraction process, and to agree upon a common list of categories and sub-categories for each survey question with text responses (Elo & Kyngäs, 2008). We also worked together to decide how these categories and sub-categories fit together to describe the data accurately.

## Results

We collected demographic information from DSP participants as listed in Table 1. DSP participants ( $n = 186$ ) indicated that their offices served an average 548 students with disabilities and an average of 28 students with ASD ( $n = 169$ ). Most participants (93.8%,  $n = 198$ ) indicated they had personal experiences interacting with family members of students with ASD.

Table 1. Demographic information of DSPs

Variable	n	%
Job Titles		
Director	89	42.2
Coordinator	63	22.7
Other	39	18.5
Assistant Director	13	6.2
Graduate Assistant	1	0.5
Type of Institution		
4-year Public College/University	84	39.8
4-year Private College/University	59	28
Community/Junior College	48	22.7
Other	9	4.3
Technical School/College	3	1.4
Size of Institution (i.e., Total Number of Students)		
More than 25,000 Students	34	16.1
10,001-25,000 Students	52	24.6

5,001-10,000 Students	32	15.2
1,000-5,000 Students	74	35.1
Under 1,000 Students	9	4.3
No Response	10	4.7

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### Research Question #1 Results

The purpose of this research question was to examine the need for family involvement of students with ASD at the postsecondary level. The majority of participants (93.8%,  $n = 198$ ) had interacted with family members and 66.8% ( $n = 141$ ) rated those experiences as positive, while an additional 21.8% ( $n = 46$ ) indicated a neutral stance. Only 11% ( $n = 22$ ) of DSPs reported that their offices offer specific services or programming that include family members. This programming includes orientation sessions, progress reports, summer transition programs with family member sessions, and informational meetings and workshops. One professional reported,

I think we do a decent job of doing a long intake session, with parents and students, to prepare the family for the adjustment. We often spend a good amount of time throughout the student's tenure here working in a triad to promote success.

About half (44%,  $n = 88$ ) of DSPs reported that they engaged in pre-enrollment outreach efforts to prepare students and family members about what to expect at the college level. These efforts included transition fairs, targeted workshops, and informational sessions. DSPs acknowledged the need for more formal services that include family members at the postsecondary level, however some reported a lack of funding and resources to establish these services at this time.

### Research Question #2 Results

The purpose of this research question was to examine the perceived needed and fulfilled roles for family members. Figure 1 provides a frequency distribution of participants' responses indicating roles they think family members *should* fulfill compared to roles family members are *actually* fulfilling while their student is enrolled in school. The roles listed for participants to choose from were based on a systematic review of the literature (Dallas et al., 2015) and a pilot study conducted by the researchers, as mentioned in the Methods section.

**Quantitative analysis.** In order to examine statistical differences in roles DSPs think family members *should* fulfill versus roles they *actually* fulfill, we completed a binary logistic regression with random effect. This type of analysis was appropriate since each individual participant indicated roles for the *should*, as well as *actual* categories. Participants were asked to check one or more boxes if they perceived that family members should fulfill certain roles. Additionally, they were asked if they perceive that family members actually fulfill those roles while the student is enrolled in school. For purposes of the analysis, a 1 indicated that a box was checked (i.e., interpreted as "yes") and a 0 was assigned to boxes that were not checked (i.e., interpreted as "no"). Outlined below are statistically significant differences between *should* and *actually* fulfilled roles. The two mean (i.e.,  $M = 0$  to 1) scores listed below indicate *should* fulfill and *actually* fulfill, respectively. These means can also be interpreted as percentages, that indicate the percentage of participants that checked a box indicating "yes": *Encourage the independence of the student*,  $F(1, 420) = 63.996$ ,  $p < .000$ , ( $M = .93$ , .64), *Reinforce what is expected of students in college*,  $F(1, 420) = 85.893$ ,  $p < .000$ , ( $M = .93$ , .60),

*Emotional Support*,  $F(1, 420) = 21.463, p < .000, (M = .91, .77)$ , *Attend ongoing on-campus meetings related to student*,  $F(1, 420) = 9.714, p < .002, (M = .19, .31)$ , *Organizational/Time management support*,  $F(1, 420) = 17.645, p < .000, (M = .62, .44)$ , *Advocate for student to receive appropriate services on-campus*,  $F(1, 420) = 45.664, p < .000, (M = .38, .67)$ , *Academic Support* (e.g., note taker, tutor),  $F(1, 420) = 6.909, p < .009, (M = .08, .16)$ , *Non-academic support as appropriate* (e.g., hygiene, money-management, transportation, laundry),  $F(1, 420) = 7.469, p < .007, (M = .72, .61)$ , *Role-play social situations*,  $F(1, 420) = 71.812, p < .000, (M = .5, .18)$ , *Regular communication with student about academic progress*,  $F(1, 420) = 19.008, p < .000, (M = .71, .54)$ , *Communicate directly with faculty*,  $F(1, 420) = 66.214, p < .000, (M = .03, .3)$ , *Ongoing communication with disability support staff* (e.g., e-mail, phone, progress reports),  $F(1, 420) = 40.999, p < .000, (M = .33, .61)$ , *Assist with communication to other offices on campus on behalf of student*,  $F(1, 420) = 68.961, p < .000, (M = .12, .43)$ . Figure 1 provides a bar graph comparing roles that family members *should* fulfill and *actually* fulfill.

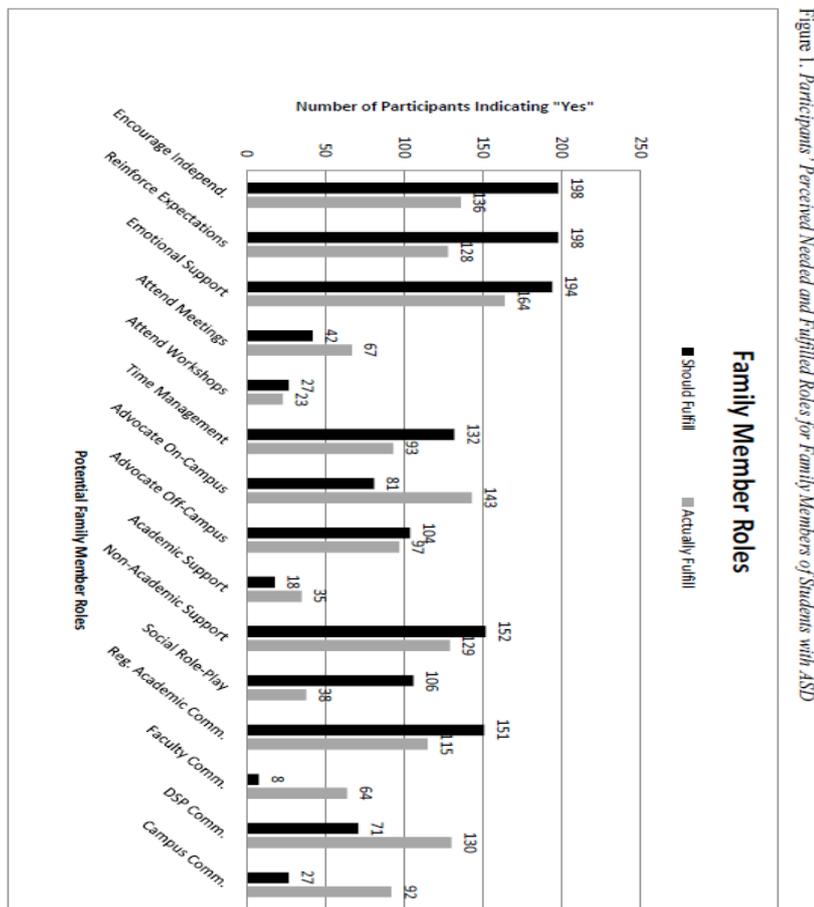


Figure 1. Participants' Perceived Needed and Fulfilled Roles for Family Members of Students with ASD

The only two roles that participants cited that family members should fulfill and actually fulfill that matched (or were not significantly different) were *Attend on-campus workshops related to student* ( $M = .12, .10$ ) and *Advocate for student to receive appropriate services off-campus* ( $M = .49, .45$ ). Additionally, Independent samples *t*-tests and Analysis of Variance (ANOVA) tests indicated no significant differences among DSP responses based on type of institutions (e.g., 4-year vs. 2-year), overall size of school, number of students with disabilities served, number of students with ASD served, or those DSPs with different job titles.

**Qualitative analysis.** In one question, we asked participants, “*In general, do you think family members should be involved non-academically with students with ASD while enrolled in college (e.g., hygiene help, time-management, paying bills, laundry)?*” The one main category that emerged through qualitative data analysis included: *Family members can be helpful by scaffolding independent living skills.* This means that DSPs thought that family members were best suited to help build and support the independent living skills of their students. One main quote to exemplify this category is from one DSP:

Often individuals struggle to maintain both academics as well as independent living at the same time due to organization, executive function, and social factors. Having support with non-academic areas can allow the student with ASD to function better academically as the number of areas needing close management is mitigated by parent/family involvement.

Sub-categories also emerged during analysis of this question. One sub-category included: *Skills should be taught prior to college.* DSPs indicated that many non-academic skills such as time management and hygiene should be taught by family members prior to the start of college. One DSP mentioned,

The transition needs to start before they get to college. Learning to be more independent while in high school (i.e., doing their own laundry, learning to bathe on a daily basis, learning to utilize technology to manage their time) is essential to success in college.

Another sub-category that emerged was that *Family involvement is often needed for all students.* In other words, DSPs acknowledged that many new college students need support from family members. A response from one DSP clearly expressed his or her thoughts: “In general, family members are involved non-academically with typical students, therefore, why should they not be involved non-academically with a student with a diagnosis of ASD?”

We asked participants, “*In general, do you think family members should be involved academically with students with ASD while enrolled in college (e.g., as a note taker, tutor, contacting instructors, etc.)?*” There were three categories that emerged from data analysis of this question. Results indicated that when family members are involved academically, *Family members should be in a secondary support role* and *When possible, a third-party should be used for academic supports (e.g., tutors, homework assistants) that schools cannot provide.* Finally, DSPs clarified that *Academic involvement by family members puts student development at risk.* Through these three main categories, DSPs were suggesting that family members not take the academic support roles, but rather help their students find third-parties to fulfill those roles if needed. When family members step into these academic roles, they often hinder the development of their student. One DSP mentioned,

All individuals need to know how to function appropriately in life and work. By completing these tasks for their student/loved one, the risk of not learning basic tasks due to dependency and lack of independence promotes higher risk for unemployment, poverty, and [low] self-worth. On the reverse, students on the spectrum need to be supported and scaffolded into this new experience.

### Research Question #3 Results

**Qualitative analysis.** When we asked participants *How do you think students with adequate family support do success-wise versus students without family support?* Two categories emerged from these reactions: *Insufficient support hinders student success* and *Over-involvement hinders student success*. DSPs emphasized that there are often problems for students when there is not a balance of support from the families. One DSP mentioned, “When families basically do everything, often the students struggle more emotionally, have strained relationships with faculty and have lower grade point averages which often lands them in academic suspension or probation.” Another DSP reported,

It is a fine line. . . . If the parent is willing to be involved but not in an overbearing, overly involved fashion, then students tend to be more successful. Over involvement can cause a backlash with a student who is trying to develop his/her own independence.

Primarily, though, participants acknowledged that the balance between parent involvement and student needs can help to facilitate a more successful experience for the student. The category that emerged to describe this balance was: *Appropriate family support promotes success*. This category represents statements from participants such as,

Family support (or lack thereof) is established early in a student's life. A student (typical or with ASD) has a greater opportunity to succeed with familial support. College is a transition period, and without support it is difficult for many individuals to know how to handle different circumstances.

Another participant reported,

The students I have worked with who have family support attend class regularly, keep up with their course requirements, follow through with appointments, ask good questions to assist them in navigating campus and educational requirements versus students without family support who are more often lost with the above mentioned and struggle more easily.

In addition to the outcomes just mentioned, other participants have noticed positive outcomes when appropriate family support is present including: higher grade point average (GPA), increased confidence, better attendance, and overall better adjustment to college.

Conversely, some DSPs reported that sometimes there may be conflicting variables that hinder a student’s success no matter the level of family support. One DSP reported,

My experience is that there are too many variables to make that kind of a relational evaluation. There are some students that fail horribly with adequate family support because of factors beyond that support. There are other students who succeed without support.

Additionally, some DSPs mentioned that students may succeed because of supports from other sources when family members are unable to provide the support,

Students on the spectrum can do very well provided they get the right kind of support from the right kind of person. Sometimes the student's parent is not able

or capable of giving the types of support needed. Some students with parents who are not capable of helping are actually better at helping themselves because they had to develop those skills and connect to people and supports through other systems.

## Discussion

Results from the current study suggest that, according to DSPs, there is a need for some level of active family member involvement and that it may support positive student outcomes. These results add to the existing literature examining family member involvement among college students with ASD and outline specific roles that members may fill, from the perspective of DSPs. Findings from the first research question suggest that most DSPs have experience interacting with family members of students with ASD, generally have positive experiences with family members, yet do not formally include family members in their programming. This finding is somewhat consistent with Barnhill's (2016) report that family member involvement varied greatly depending upon the institution. It is unclear if the lack of programming for the inclusion of family members is due to a lack of institutional mandate and resources, lack of student willingness, or due to a belief that students should act independently in all aspects of college life.

Results from the second research question suggest that DSPs perceive differences between the roles that family members should fulfill compared to roles they actually fulfill. For example, when asked about academic versus non-academic support, DSPs were largely more in favor of non-academic support and very few indicated that they thought family members should be providing direct academic support. Non-academic support was described as independent living skills that should be taught prior to college and are necessary for all students to learn, including those without disabilities. These findings were consistent with Dallas et al. (2015) who reported that the most appropriate family member roles seem to be related to non-academic areas of support.

There were statistically significant differences regarding roles that participants thought family members should fulfill compared to roles family members are actually fulfilling. DSPs in the current study thought that family members should increase actions related to the following roles: *Encourage the independence of the student*, *Reinforce what is expected of students in college*, *Emotional Support*, *Organizational/Time management support*, *Non-academic support as appropriate (e.g., hygiene, money-management, transportation, laundry)*, *Role-play social situations*, and *Regular communication with student about academic progress*. These roles were consistent with previous studies outlining family member roles that included help with money management, laundry, and appointments (Morrison et al., 2009), medical records and transportation (Szentmiklosi, 2009), social coaching and living near students (Schlabach, 2008).

DSPs in the current study thought that some family members do too much and should decrease actions related to the following roles: *Attend ongoing on-campus meetings related to student*, *Advocate for student to receive appropriate services on-campus*, *Academic Support (e.g., note taker, tutor)*, *Communicate directly with faculty*, *Ongoing communication with disability support staff (e.g., e-mail, phone, progress reports)*, *Assist with communication to other offices on campus on behalf of student*. These findings are consistent with Schindler et al. (2015), who reported that over-involvement of family members in areas such as homework help and decision making was associated with slowed development of academic skills and self-advocacy skills. Szentmiklosi (2009) described one instance of a family member acting as a note taker for their son or daughter. We have interpreted these particular roles as areas in which

DSPs expect students with ASD to increasingly become more independent, self-advocate, and excel academically.

Research question three examined family involvement and student outcomes. Even though participants qualitatively discussed family member over-involvement and under-involvement as negatively affecting student success, we found no definitive evidence showing a relationship between family involvement and student outcomes. Although previous research suggested that an appropriate amount of family member involvement is important and helpful (Dallas et al., 2015; Schindler et al., 2015), it remains unclear how this involvement impacts student outcomes.

### **Limitations**

Several limitations existed in the study. First, the response rate was low, with only 7.6% of AHEAD members participating in the study. DSPs who did participate may have had a specific interest in students with ASD and family member involvement, which may have impacted survey results. The survey was self-report based and participants may have provided socially-desirable responses, indicating agreement that family member involvement is needed. We did include two survey items confirming participants had experience serving students with ASD and working with their family members, however, participants' experiences may vary widely across institutions, which may have affected survey results.

### **Practical Recommendations**

Based on the results of this study, we have outlined some recommendations for DSPs who work in postsecondary settings. DSPs who wish to include family members more formally in their programming for students with ASD may want to pursue activities such as summer transition programs, orientation sessions at the beginning of semesters, extensive initial interviews, progress reports, or other informational meetings and workshops that include family members. Any formal inclusion of family members will need to be done with the written permission of the student being served. DRCs that are unable to formally include family members in their programming should increase pre-enrollment outreach efforts to prepare students and family members for the transition to postsecondary settings. These outreach efforts may include attending high school transition meetings or fairs or providing workshops and informational sessions for high school students with ASD and their families.

An ideal triadic relationship including DSPs, family members, and students with ASD would include clear expectations for family member involvement. We recommend that DSPs share the results outlined in this study with family members in order to help them increase actions in some roles (e.g., regular communication with student) while decreasing actions in other roles (e.g., attend ongoing on-campus meetings). Providing third-party support services (e.g., tutor, homework assistant) might alleviate the need for family members to feel like they need to stay involved, especially in roles that would be considered direct academic support. Third-party tutors and homework assistants are typically not considered free, reasonable accommodations provided by DRCs and a cost is often associated with hiring individuals to provide this service. Therefore, DSPs should be prepared to help students and family members find resources to help cover these extra costs. For example, state division of rehabilitation services (DRS) programs may help cover the costs of tutors or homework assistants for eligible postsecondary students with disabilities. Another option is for postsecondary DRCs to establish volunteer programs that enlist college student volunteers to provide free tutor and homework assistant services for students with disabilities.

It is apparent that DSPs think family member involvement is important, but must be balanced with increasing the independence of students with ASD while enrolled in school. Therefore, it may be helpful to decrease the level of family involvement over time. For example, gradually decreasing family member involvement in on-campus meetings, phone meetings, or e-mail messages over the course of a student's first semester. This is another clear expectation that could be shared with students and family members during the transition to postsecondary settings.

Finally, it is recommended that DRCs routinely collect demographic and student outcome data (e.g. retention rates, graduation rates, GPAs) so that more research on postsecondary students with disabilities can take place. This data would also be helpful for internal program evaluation. Originally, we intended to use de-identified student GPAs to help address research question three. However, only 4.7% of participants had access to student outcome data or were willing to send this information. We would not have been able to perform statistical analyses on this small data set. It is apparent from this study and others (Barnhill, 2016) that not all DRC offices routinely collect outcome data on students.

### Future Research

Future research should be aimed at family members and college students with ASD regarding support roles that family members fulfill, students' perspectives on these roles, and the relationship between family member actions and student academic outcomes. It is important to gain student perspectives, as they are the most important stakeholder in the postsecondary setting. The survey used in the current study could be modified for use with student and family member research participants. Additionally, future research should examine DRCs that include family members in their formal programming and examine protocols or guidelines these offices use to work with family members. Only 11% of participants in the current study reported including family members in their support programming. This research would help to further understand how DRCs work to include family members (e.g., progress notes, interview), yet foster the growth and independence of students they serve.

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