



**Northern Illinois University**

# Family Involvement in Postsecondary Settings for Students with Autism Spectrum Disorder

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## Introduction

- ❖ It is estimated that 1 in 50 children are diagnosed with Autism Spectrum Disorder (ASD) and the prevalence of cases is increasing.<sup>1</sup>
- ❖ While 80% of postsecondary students with ASD were working toward some type of diploma, certificate or license, only 39% completed school.<sup>2</sup>
- ❖ Students with ASD have different levels of executive functioning and social issues; both are areas where students may need support in college.<sup>4, 5</sup>
- ❖ Some ASD experts recommend more family involvement and that communication between Disability Support Professionals (DSPs) and family members should be ongoing.<sup>3</sup>
- ❖ If parents or other family members are to have significant roles in postsecondary educational environments, it will be important for campus DSPs to know these specific roles and how family members can help support college students with ASD.
- ❖ Little empirical evidence exists indicating whether family involvement is beneficial to postsecondary students with ASD and specific support roles family members may fill.<sup>5</sup>

***“We are very mindful of the fact that, from probably kindergarten to 12<sup>th</sup> grade, parents have been very involved . . . our philosophy is, you don’t just cut that off when the student turns 18.”*** –Harper College

## Purpose

- ❖ Examine identified role(s) of family members of students with ASD in postsecondary educational settings.
- ❖ Determine if family involvement in postsecondary educational settings results in positive outcomes for students with ASD.
- ❖ Conduct a pilot study to help develop future studies on the topic of postsecondary students with ASD and family involvement.

## References

- <sup>1</sup>Shattuck, P. T., Narendorf, S. C., Cooper, B., Sterzing, P. R., Wagner, M., & Taylor, J. L. (2012). Postsecondary education and employment among youth with an autism spectrum disorder. *Pediatrics*, 129, 1042-1049.
- <sup>2</sup>Newman, L., Wagner, M., Knokey, A.-M., Marder, C., Nagle, K., Shaver, D., Wei, X. (2011). The post-high school outcomes of young adults with disabilities up to 8 years after high school. *A Report from the National Longitudinal Transition Study-2 (NLTS2)* (NCSE 2011-3005). Menlo Park, CA: SRI International.
- <sup>3</sup>Wolf, L. E., Thierfeld Brown, J., & Bork, G. R. K. (2009). *Students with asperger syndrome: A guide for college personnel*. Shawnee Mission, KS: AAPC Publishing
- <sup>4</sup>Camarena, P. M. & Sarigiana, P. A. (2009). Postsecondary educational aspirations of high-functioning adolescents with autism spectrum and their parents. *Focus on Autism and Other Developmental Disabilities*, 24(2), 115-128.
- <sup>5</sup>Dallas, B., Ramisch, J., & McGowan, B. (in press). Students with autism spectrum Disorder and the role of family in postsecondary settings: A systematic review of the literature. *Journal of Postsecondary Education and Disability*.

## Methods

- ❖ Contacted DSPs at 14 community colleges within a 50 mile radius of NIU via email requesting an in-person interview.
- ❖ 8 Disability Resource Centers (DRCs) (11 staff) scheduled interviews, and were sent 3 pre-interview questions prior to the appointment.
- ❖ 10 DSPs were interviewed at their office and 1 was interviewed over the phone; interviews were audio recorded to ensure accuracy.
- ❖ DSPs were asked a series of questions, including:
  - ❖ Statistical questions (how many students are diagnosed with ASD, etc.)
  - ❖ Their personal philosophy on family involvement.
  - ❖ Describing their encounters with family members as positive, negative, or neutral.
- ❖ On average, the interviews lasted for 29 minutes (range=13-47 minutes).
- ❖ Data and findings were compiled and condensed into a table. Then, the general information from the table was used to group answers that had similarities or distinguish outliers.

**Table 1**

| Accommodations Not Required by Law        | Number of Colleges Offering Accommodation |
|---|---|
| Communication between professors and DSPs | 6   |
| Letters of Introduction                   | 2   |
| Courses for students with ASD             | 2   |
| Tutors                                    | 4   |
| Frequent/Regular Meetings                 | 2   |

***“...now it’s time to pass the torch onto me.”***  
–Morton College

## Results

- ❖ 5 out of 8 DRCs reported that more than 75% of students sign a release form allowing communication with family members.
- ❖ All DSPs reported that their offices offer some type of accommodation that is not required by law (Table 1)
- ❖ 6 of the 8 DRC offices did not have a specific method for working with family members of students with ASD.
- ❖ 6 of the 8 colleges did not offer specific programs or classes for students with ASD.
- ❖ 2 colleges had support groups specifically for family members of students with ASD.
- ❖ One office had a “Transition Autism Program” that was grant-funded and was designed to “bolster success in academics, improve interpersonal relationships, and ultimate credit completion”.
- ❖ 5 out of 8 colleges attend IEP meetings with families to help with the transition to college.
- ❖ When asked about their overall experience with family members, 5 out of 8 DRCs talked about frequently contacting families.
- ❖ 7 DSPs reported positive experiences and 1 reported neutral with family members of students with ASD.
- ❖ The most common personal opinion of DSPs regarding family member involvement was that they should be involved, and their role should be support. (Table 2)
- ❖ Many DSPs reported that students with ASD who had family support were more successful.

**Table 2**

| Family Roles Mentioned   | Number of Colleges |
|--------------------------|--------------------|
| Promote Independence     | 2                  |
| Communication Assistance | 2                  |
| Help with Expectations   | 4                  |
| Support                  | 5                  |

***“I feel like students wouldn’t be nearly as successful if we weren’t able to work collaboratively.”***

–Illinois Valley Community College

## Discussion

- ❖ Due to the increase in prevalence of ASD nationally, more students with ASD may be seeking services in college. Therefore, more ASD specific programs may be needed in the future.
- ❖ Based on DSPs’ reports, family involvement may be beneficial and promote success among college students with ASD.
- ❖ DSPs identified potential family support roles and indicated that experiences with family members were mostly positive.
- ❖ A small percentage of youth with ASD attend college; this study was consistent with previous research in that only 7.6% of active students enrolled in DRC offices have ASD.<sup>2</sup>
- ❖ Aligning with previous research on the topic, it was found in this study that students with ASD had different levels of functioning and thus required different accommodations.
- ❖ Many DRC professionals reported that they met regularly with certain students to improve executive functioning and social skills.<sup>4, 5</sup>

## Limitations

- ❖ The DRCs represented in this study are those only within a 50 mile radius of NIU and are thus not nationally representative of all DRC offices.
- ❖ Only 2 colleges had support groups specifically for post-secondary students and families with ASD.

## Recommendations

- ❖ Future studies should examine accommodations that DRCs offer beyond those required by law, as well as the protocols they use to work with family members.
- ❖ A future study also should utilize a larger sample size of DSPs at colleges across the United States.
- ❖ The findings of this research will be used to develop a survey to further examine college students with ASD and family member involvement.