

Self-Advocacy and Post-Secondary Success of Students with Autism Spectrum Disorder (ASD)

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Abstract

Administrators in secondary and post-secondary education are supporting increasing numbers of students with autism spectrum disorder (ASD) who are interested in attending college or other post-secondary settings. Self-advocacy skills play a critical role in the academic and non-academic success of students with ASD. Few, if any, studies have been conducted to examine tools or procedures to help school systems determine the self-advocacy skills of their students with ASD. This study built on existing research in college supports for individuals with ASD by examining the utility of a specific survey to assess self-advocacy factors that affect student success. Administrators in Bengaluru, India used the survey to sample educators' perceptions of the self-advocacy skills of their transition-age students with ASD. Results from data collected suggest that this survey could be used to determine the overall likelihood of post-secondary success of a student group based on several key self-advocacy indicators. Specific self-advocacy domains needing increased support were also generated by the survey. Implications for secondary and post-secondary leaders interested in developing the self-advocacy skills of their students are discussed.

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Nearly 500,000 young people with autism spectrum disorder (ASD) will make the transition to adulthood in the next decade in the United States. Neurodiverse people, including those with ASD, face challenges as they make this transition; struggles with post-secondary education, employment, living arrangements, community participation, health, and safety are commonly reported (Roux, Shattuck, Rast, Rava, and Anderson, 2015). Young adults with ASD in transition often find themselves with little or no support after leaving their childhood homes as the structured programs and entitlements of young life disappear. Self-advocacy and self-determination skills have been shown to play a vital role in navigating this transition period as students with ASD access resources and make important life decisions (Ryan and Griffiths, 2015).

Self-advocacy has countless definitions in the research literature. For the purpose of this work, the authors defined self-advocacy as the ability to communicate one's wants and needs (Paradiz, 2009; Paradiz, Kelso, Nelson, and Earl, 2017; Test, Fowler, Wood, Brewer, and Eddy, 2005). Successful self-advocacy often relies on the degree to which a person has developed competencies in the following three areas: self-awareness, or knowing one's strengths, tendencies, and needs; competence, or having the tools to advocate for oneself; and autonomy, or initiating advocacy on one's own behalf, independent of prompts or cues (Paradiz, 2013). Disclosing one's diagnosis to others and developing self-advocacy plans and scripts are also important skills in one's self-advocacy repertoire (Paradiz, 2009).

Self-advocacy involves more than just asking for help. Awareness of the laws and policies relevant to one's diagnosis is crucial, as is active participation in meetings to determine one's life course (Shore, 2004). Greater self-advocacy leads to positive increases in self-concept, leadership ability, belonging, and one's impact on community (Paradiz et al., 2017; Ryan and Griffiths, 2015; Vaccaro, Daly-Cano, and Newman, 2015). Self-advocacy training and support for people with ASD is not limited to youth in transition or adults and can begin to inform the lives of children with ASD as well. Paradiz et al. (2017) stated that "self-advocacy requires that a young person with autism develop awareness of his or her needs, preferences, interests, and rights and build competencies in implementing strategies to attain them" (p. 3). Self-advocacy goals are recommended across broad categories as young people with ASD prepare for transition (U.S. Government Accountability Office, 2016).

Self-determination, or the ability to set and pursue one's goals (Ryan and Griffiths, 2015), is closely related to self-advocacy. Wehmeyer (1992) defined self-determination as "the attitudes and abilities required to act as the primary causal agent in one's life and to make choices and decisions free from undue external influence and interference" (p. 305). Teaching and supporting self-determination skills during times of transition can lead to improved outcomes in employment and financial independence (Wehmeyer and Palmer, 2003). Paradiz et al. (2017) stated "ensuring that students with autism not only understand their differences, but also have the liberty and power to act on their needs and rights, is one of the most essential lessons we can impart to them before they transition to adulthood" (p. 8). Self-determination, in concert with self-advocacy, is essential to effective leadership which can be seen as collective self-determination (Johnson, 1999).

Significant numbers of the 500,000 transitioning young adults with ASD in the United States are likely to pursue post-secondary options in the next decade. Secondary and post-secondary administrators and personnel will play ever-increasing roles in the preparation and

support of said students. Several key factors associated with successful college experiences have been identified through research by pioneers in the field of college programming for students with ASD. Ellison, Clark, Cunningham, and Hansen (2013) identified self-advocacy skills as necessary for academic and non-academic success for college students with ASD. A Delphi survey panel of experts agreed that self-advocacy is a top challenge for college students with ASD (Ellison, 2013; Ellison et al., 2013). While self-advocacy is recognized as critical for post-secondary success, an established process or tool for assessing the self-advocacy skills of transitioning students with ASD does not exist. The need for such a protocol is especially paramount in situations where assessing large groups of students from school districts or counties is required for targeted self-advocacy training and support.

Method

The purpose of this study was to explore the effectiveness of a survey tool for assessing self-advocacy and related skills of a group of transition-age students with ASD. Specifically, researchers were interested in educator responses to survey items tied to a variety of self-advocacy domains and the utility of those responses for generating training plans for students and school systems. The research questions were:

1. Can survey data on the self-advocacy skills of transition-age students with ASD provide indicators about the likelihood of that group's post-secondary success?
2. Can specific self-advocacy domains be identified as possible areas for targeted training and support to help educational systems better prepare students with ASD for success in post-secondary settings?
3. Do educators want greater support in their students' self-advocacy preparation?
4. Are educators open to receiving self-advocacy training and help from adults with ASD?

Setting and Participants

The authors of this report have been involved in various educational projects outside of the United States. For one author, projects included multiple trips to South India to support people with ASD (Ramamoorthi and Nelson, 2011) and provide training for educators and families. Self-advocacy, self-determination, and leadership opportunities for individuals with ASD seemed low or non-existent in many of the schools and communities visited during those trips. As a result, planning and coordinating efforts were increased to design programs to help school systems and students better understand self-advocacy. Partners at the ASHA Assessment, Training, and Guidance Centre in Bengaluru, India hosted a three-hour self-advocacy workshop for special educators in July of 2017. Twenty-four autism educators from the city of Bengaluru attended the workshop.

Materials and Procedure

A brief survey tool called the *ASD Self-Advocacy and Leadership Survey* was designed by the authors and shared with the ASHA Assessment, Training, and Guidance Centre. The survey had 23 questions, used a combination of percentage and yes/no questions, and had been piloted with special educators in the United States prior to use by the ASHA Centre. Educators who taught students with ASD ages 14 and above were asked to volunteer to take the brief survey following the three-hour workshop in Bengaluru. The age of 14 was chosen as the student cutoff as it is widely recognized as the beginning of transition for young adults in the United States (Roux et al., 2015). Of the 24 total educator attendees, 46% ($n = 11$) completed the survey. The ASHA Assessment, Training, and Guidance Centre hosted both the workshop and study, and permission to share data results was granted to the authors.

Results

Data in Table 1 show educator perceptions of the self-advocacy skills of their students with ASD. Scores indicated that a high percentage of students with ASD in Bengaluru likely do not know they have a diagnosis (73% of responses in 0-20% range). As a result, student disclosures of their diagnoses are almost non-existent (100% of responses in 0-20% range), and many are unaware of common terms used to describe ASD (64% of responses in 0-20% range). Very few students know about laws and policies relevant to their diagnosis (82% of responses in 0-20% range), and small numbers of students with ASD are reported to attend relevant meetings about their services and supports (64% of responses in 0-20% range).

Educator responses suggest that some students with ASD are able to identify sources of comfort (9% of responses in 0-20% range) and discomfort (9% of responses in 0-20% range), and a significant portion of students are believed to be able to ask for help to get their needs met (27% of responses in 0-20% range). A moderate percentage of the surveyed educators in Bengaluru believed their students would benefit from learning more about their own diagnosis of ASD (36% of responses in 0-20% range). All surveyed educators who responded were interested in receiving educational support and consultation from trained professionals with ASD (100% Yes responses, 2 did not respond). These data are not listed in Table 1.

A total of 14 survey items and their response data were omitted from this report. Some items did not relate to the research questions addressed in this study or were based on prerequisite skills that students were missing. For example, some survey items about the leadership skills of students with ASD were rendered irrelevant due to students' apparent lack of awareness of their diagnoses and missing disclosure experiences.

Table 1
Educator Responses to
ASD Self-Advocacy and Leadership Survey
Bengaluru (n = 11)

Percentage of students who...						
Survey Item	0-20%	21-40%	41-60%	61-80%	81-100%	No Response
know they have an ASD diagnosis	8	3				
have disclosed their diagnosis to others	11					
are aware of common terms used to describe ASD	7		4			
know about the laws and policies relevant to ASD	9	2				
participate in meetings about their services and supports	7	3	1			
can identify things that comfort them	1	5	4		1	
can identify things that discomfort them	1	5	2	2	1	
can ask for help to get their needs met	3	1	3	4		
would benefit from learning more about their ASD diagnosis	4	3	1	3		

Discussion

The *ASD Self-Advocacy and Leadership Survey* provided relevant information for this study's research questions. For example, data collected provided some indication of the likelihood of post-secondary success of the educators' students; one could conclude that a small percentage of students with ASD in Bengaluru have the self-advocacy skills needed to meet the academic and non-academic demands of post-secondary life. The survey produced strong evidence of educators' interest in receiving increased educational support in self-advocacy, and consultation from trained professionals with ASD was also a near-unanimous interest. Finally, survey results generated specific self-advocacy domains that could be targeted for training to help educational systems better prepare students with ASD for success in post-secondary settings.

Based on these survey results, leaders in secondary and post-secondary settings could design an action plan, focused on self-advocacy, to better prepare students with ASD in Bengaluru for college success. Such a plan might include the following key points:

- assess why parents and educators are reluctant to tell students about their ASD diagnoses;
- work on building a stronger culture of ASD awareness and acceptance at the secondary and post-secondary levels;
- increase secondary and post-secondary students' access to relevant laws and rights affecting their lives;
- work to increase student participation in meetings about their school supports and services;
- use student strengths in identifying sources of comfort, discomfort, and asking for help from others to introduce self-advocacy terminology and concepts in secondary school settings;
- find students who are above average in ASD knowledge and self-advocacy foundations to serve as peer supports for other students;
- help secondary and post-secondary students learn more about their ASD diagnoses and how it affects their lives; and
- increase staff development and training in self-advocacy.

Limitations and Future Research

The sample size of surveyed educators in this study was small and responses were based on educator perceptions only. Also, the survey was a cross-sectional convenience sample and lacked the rigor of a randomized control trial. Deep statistical analysis was difficult and survey tool refinement is required to increase statistical applications. Also, the survey tool was still in early stages of application and its validity and reliability were not fully known.

Future research is needed to determine best practices which help leaders in secondary and post-secondary education identify and meet the self-advocacy needs of their students with ASD, especially in terms of transitions to post-secondary settings. Examining collaborative models between secondary and post-secondary leaders to help students with ASD achieve post-secondary success would be useful. Studies to determine educators' needs to better understand and teach self-advocacy skills to their students is also needed. Finally, authentic coaching in self-advocacy from trained individuals with ASD is a support method worthy of deeper investigation.

Conclusion

Self-advocacy skills play a critical role in the academic and non-academic success of students with ASD. Administrators and professionals in secondary and post-secondary education are likely to encounter increasing numbers of students with ASD who are interested in attending

college or other post-secondary settings. Few, if any, studies have been conducted to develop tools or procedures to help school systems determine the self-advocacy skills of their students with ASD. This study built on existing research in college supports for individuals with ASD by examining the utility of a specific survey to determine some of the self-advocacy factors that affect student success. Though the understanding in this area is in its infancy, this study began an important, new research step in self-advocacy supports for post-secondary students.

References

- Ellison, L. M. (2013). *Assessing the readiness of higher education to instruct and support students with Asperger's Disorder*. (Doctoral dissertation). Retrieved from <http://mds.marshall.edu/etd> (Paper 428).
- Ellison, M., Clark, J., Cunningham, M., & Hansen, R. (2013). Academic and campus accommodations that foster success for college students with Asperger's Disorder. *Southern Regional Council on Educational Administration 2013 Yearbook: Jazzing It Up*, 65-76.
- Johnson, J.R. (1999). Leadership and self-determination. *Focus on Autism and Other Developmental Disabilities*, 14(1), 4-16.
- Paradiz, V. (2009). *The integrated self-advocacy ISA curriculum: A program for emerging self-advocates with autism spectrum and other conditions*. Shawnee Mission, KS: Autism Asperger Publishing Co.
- Paradiz V. (2013). Integrated self-advocacy ISA® assessments. Center for Integrated Self Advocacy. Retrieved from www.autismselfadvocacy.com
- Paradiz, V., Kelso, S., Nelson, A., & Earl, A. (2017). Essential self-advocacy and transition. Manuscript submitted for publication.
- Ramamoorthi, P., & Nelson, A. (2011). Drama education for individuals on the autism spectrum. In Shifra Schonman (Ed.), *Key Concepts in Drama/Theatre Education* (pp.177-181). Rotterdam, Netherlands: Sense Publications.
- Roux, A.M., Shattuck, P.T., Rast, J.E., Rava, J.A., & Anderson, K.A. (2015). National autism indicators report: transition into young adulthood. Philadelphia, PA: Life Course Outcomes Research Program, A.J. Drexel Autism Institute, Drexel University.
- Ryan, T.G., & Griffiths, S. (2015). Self-advocacy and its impacts for adults with developmental disabilities. *Australian Journal of Adult Learning*, 55(1), 31-53.
- Shore, S. (Ed.). (2004). *Ask and tell: Self-advocacy and disclosure for people on the autism spectrum*. Shawnee Mission, KS: Autism Asperger Publishing Co.
- Test, D.W., Fowler, C.H., Wood, W.M., Brewer, D.M., & Eddy, S. (2005). A conceptual framework of self-advocacy for students with disabilities. *Remedial and Special Education*, 26(1), 43-54. doi: 10.1177/07419325050260010601
- U.S. Government Accountability Office. (2016). Youth with autism: Roundtable views of services needed during the transition into adulthood. (Publication No. GAO-17-109). Retrieved from GAO Reports Main Page via GPO Access database: <http://www.gpoaccess.gov/gaoreports/index.html>
- Vaccaro, A., Daly-Cano, M., & Newman, BM. (2015). A sense of belonging among college students with disabilities: an emergent theoretical model. *Journal of College Student Development*, 56(7), 670-686. doi: 10.1353/csd.2015.0072
- Wehmeyer, M.L. (1992). Self-determination and the education of students with mental retardation. *Education and Training in Mental Retardation*, 27(4), 302-314.
- Wehmeyer, M.L., & Palmer, S.B. (2003). Adult outcomes for students with cognitive disabilities three-years after high school: the impact of self-determination. *Education and Training in Developmental Disabilities*, 38(2), 131-144.