

# A Measurement of Self-Advocacy Awareness in Young Adults with Intellectual and Developmental Disabilities

Megan Roome, B.S., Audrey Wood, B.A., & Debora Downey, PhD, CCC-SLP

**Research Mentor:** Debora Downey, PhD, CCC-SLP

## Objective

The ability to effectively self-advocate, or communicate one's wants and needs, is critical for young adults with intellectual or developmental disabilities (IDD) transitioning into adulthood. Increasing numbers of individuals with IDD are pursuing post-secondary education, work, and independent living; however, many of these individuals do not receive the accommodations and support they need beyond high school. Thus, it is important to explicitly teach self-advocacy skills to those with IDD transitioning into adulthood. Several key principles, or various types of underlying knowledge and skills, contribute to an individual's competency in self-advocacy. These include knowledge of self-advocacy skills, self-awareness of strengths and challenges, self-determination, communication skills, self-compassion, leadership skills, and knowledge of one's rights as a citizen and as an individual with a disability. Currently, there are few available curricula that teach self-advocacy skills and few feasible and accessible ways to measure students' knowledge and skills in self-advocacy.

The purpose of this study was to develop a measure that can be used to assess an individuals' acquisition and understanding of the key principles of self-advocacy. This measure was used in order to determine whether young adults with ID have learned important principles of self-advocacy in the setting of a postsecondary education program.

## Methods

The researchers developed a 23-question survey intended to measure an individual's knowledge and application of each of the seven key principles of self-advocacy identified in the literature. It was primarily based on *ME! Lessons for Teaching Self-Awareness and Self-Advocacy*, an evidence-based curriculum developed at the University of Oklahoma. All questions were carefully selected from the program's unit quizzes and written and/or adapted with consideration of reading level. True/false and multiple-choice questions were determined to be a more accessible method for measuring knowledge than open-ended questions.

The final survey consisted of 14 multiple-choice questions with four possible answers and nine true/false questions written at a Fry-based reading level of grade four. The survey was administered to 47 students in a post-secondary education program at a large, Midwest university in two groups, with one group consisting of students in year 1 of the program ( $n = 22$ ), and a second group consisting of students in year 2, 3, or 4 of the program ( $n = 25$ ). All 47 students identified as having one or more disability diagnoses (e.g. Autism Spectrum Disorder, Cerebral Palsy, ADD/ADHD, learning disability, etc.). Participant ages ranged from 18 to 28 years, and Full Scale Intelligence Quotients (FSIQ) ranged from 54 to 113. Researchers administered the survey following a predetermined administration protocol, which included participants taking the survey electronically via Qualtrics and each question being read aloud.

## Results

Following each group's completion of the survey, data were analyzed to examine any patterns and differences both across and within groups. Across all 47 students, the mean percent of questions answered correctly was 79.33% ( $SD = 12.85\%$ ). The mean performance for the Year 2-4 students ( $M = 82.78\%$ ,  $SD = 10.31\%$ ) was higher than that of the Year 1 students ( $M = 75.36\%$ ,  $SD = 14.57\%$ ). This difference between groups approached significance ( $t(35) = -2.001$ ,  $p = .053$ ). There was a weak to moderate strength of correlation between student performance on the survey and FSIQ ( $r(45) = .48$ ,  $p < 0.001$ ) and Woodcock-Johnson Broad Reading level standard scores ( $r(45) = .57$ ,  $p < 0.001$ ). When

comparing average performance on each of the types of questions (i.e. multiple choice versus true/false), there was not a significant difference ( $t(9) = -0.004, ns$ ). Performance on questions related to each of the seven self-advocacy principles was also examined. Year 1 students demonstrated the most knowledge of the principle of self-determination, while year 2-4 students answered the most questions related to communication correctly. All students showed the least knowledge of their rights as individuals with disabilities.

## **Conclusions**

Generally, students who were in their second, third, or fourth year in a postsecondary education program performed better than those who were in their first year at the same postsecondary education program. There was not a formal self-advocacy curriculum in place, so this indicates that students may have learned some self-advocacy skills implicitly while participating in the transition program. Reading or cognitive levels or the type of question (e.g. multiple choice versus true/false) did not appear to independently explain or influence student performance and one's ability to respond to questions correctly.

Overall, both groups of students seem to have been exposed to self-advocacy concepts. For example, most students showed an understanding of accommodations, as most were able to identify a correct definition and example of an accommodation. However, some of the patterns of incorrect responses demonstrated that there may be some specific terminology that the students have not yet been exposed to (i.e. self-advocacy, self-awareness, barrier, responsibility, modifications). This may be related to not having received direct instruction in self-advocacy concepts that would have explicitly taught these terms. In addition, although many students seem to have been exposed to self-advocacy concepts (e.g. accommodations, goals, communication), their performance showed that they had more difficulty applying those concepts in real-life work or school scenarios.

This survey demonstrated that without direct instruction in self-advocacy skills, young adults with IDD may demonstrate gaps in their knowledge of important self-advocacy concepts and their ability to apply these skills. Specific areas that would benefit from direct instruction include knowledge of rights as citizens and as individuals with disabilities, self-awareness, perspective-taking, and both verbal and non-verbal communication skills. Additionally, young adults with IDD need to be given the opportunity to practice applying the skills they are learning in everyday life. Teaching application of skills will support long-term outcomes for this population, such as the ability to get a job and, importantly, to maintain a job.

This was a preliminary study, and further research is needed to determine whether this survey is an accurate, relevant, and useful tool for measuring self-advocacy awareness in this population. For example, future studies may use the survey as a pre-test/post-test measure following a specific self-advocacy curriculum; administer the survey to a larger group of participants to increase power and representativeness of the population; or compare performance on the survey to an individual's in vivo observations, quality of life measures, or parent/teacher ratings of self-advocacy skills.