The Role of Self-Advocacy in Self Awareness and Understanding of Disability among Individuals with Intellectual Disabilities

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Introduction

• Too often families and professionals avoid conversations regarding the details and ramifications of disability with individuals with intellectual disability (ID). Yet, in order to be the primary causal agent in one’s life, individuals need to know themselves and understand how their disability might impact their relationships, employment, participation, and need for supports (Bremer, Kachgil, & Scholler, 2003).

• The self-advocacy movement provides individuals with ID the opportunity to form a positive cultural identity (Spaansini & Friedman, 2014). Ideally, self-advocacy groups promote awareness of self and disability with the goal of helping individuals advocate for themselves.

Current Study

The current study aimed to explore how adults with intellectual disability (ID) understand their disability and the potential role self-advocacy groups play in individuals’ understanding and awareness. Specifically:

1. Are individuals in self-advocacy organizations more aware of their disabilities than those who are not?
2. How do individuals with ID describe their disability?
3. Is there a significant difference in individuals’ description of their disability based on involvement in self-advocacy groups?

Measures.

The current study utilized an expanded version of the 2014-2015 National Core Indicators Adult Consumer Survey (NCI ACS) with additional questions developed by researchers at Oklahoma State University. As part of the expanded Oklahoma version of the NCI ACS, participants were asked two questions regarding disability awareness: “Do you have a disability?” and “If so, what is your disability?”

Participants.

Participants included 552 individuals who were able to self-report answers on Section 1 of the Oklahoma version of the NCI ACS.

• Age range: 19 - 81 years (M = 48.45, SD = 12.26)
• ID classification: 52.3% mild ID, 30.7% moderate ID, 13.5% severe ID, 2.7% profound ID, and .8% unspecified ID.
• Gender: Males comprised a majority (n = 397, 63.8%) of respondents.
• Race/ethnicity: 77.9% White, 12.7% Black, 8.7% American Indian or Alaska Native, and 5% Asian.

Qualitative Data Analysis.

To ensure validity of the qualitative analysis of participants’ responses to the questions “Do you have a disability?” and “What is your disability?” a team-based approach was used to code and group themes. Team members independently coded responses then met to discuss final coding and reached a consensus for codes that differed.

Findings

Qualitative Themes: “Do You Have a Disability?”

Of the 552 individuals who answered section one, only 470 of these individuals were able to answer “Do you have a disability?” Participants’ responses revealed only a slight majority (58.5%) of adults receiving state-funded residential supports answered yes to this question.

1. Are individual’s in self advocacy organizations more aware of their disability?

A Chi Square Analysis was conducted to determine whether there were differences in self-awareness of individuals with ID based on participation in a self-advocacy group. Although a higher percentage of individuals who reported attending self-advocacy groups (72%) reported having a disability compared to individuals who did not report attending self-advocacy groups (63%), results of chi-square analysis found no significant differences in self-awareness between individuals who reported participating in a self-advocacy group and individuals who did not, χ² (2, 470) = 4.05, ρ = .13.

2. How do individuals with ID describe their disability?

Participants responses to the question “What is your disability?” were coded as Disability Avoidant (n = 12, 3%), Disability Externalized (n = 24, 6%), Disability Internalized (n = 147, 37.1%), Disability Undefined (n = 167, 42.1%), and No Response (n = 47, 11.8%).

3. Is there a significant difference in individual’s descriptions of their disability based on involvement in self-advocacy groups?

Analyses were conducted to determine whether there were differences in individual’s description of disability based on their involvement in self-advocacy. Results of chi-square analysis found no significant differences in disability description and involvement in self-advocacy groups, χ² (4, 397) = 8.205, ρ = .084.

Conclusion

The nonsignificant findings from the current study raise the question of whether self-advocacy groups are enhancing the awareness and understanding of disability. Individuals in this study are receiving state funded services for their disabilities, but may not be engaged in conversations about what having a disability means. Preliminary results from the current study indicate more efforts may be needed to help individuals with ID understand themselves and the effect their disability may have on their lives.

Funding for this research was provided through a contract with Oklahoma Developmental Disabilities Services and the Department of Human Development and Family Science at Oklahoma State University. Author Contact information: Emily Schleich, emily.schleich@okstate.edu