Recommendations of the Self-Determination and Self-Advocacy Strand From the National Goals 2015 Conference

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Abstract

This article reports the recommendations of the Self-Determination and Self-Advocacy Strand from the National Goals 2015 conference. The recommendations provide direction on research goals to advance policy and practice related to self-advocacy and self-determination over the next 10 years. Seven recommendations and multiple subrecommendations were developed over a 2-day meeting by leaders in the field of intellectual and developmental disabilities. The recommended goals provide direction for research initiatives related to collective self-advocacy and personal self-determination. Implications for the field are discussed.

Key Words: self-advocacy; self-determination; intellectual and developmental disabilities; National Goals

The self-advocacy movement has played a critical role in driving change in the disability field, articulating the need to shift power to people with intellectual and developmental disabilities (IDD) and create the infrastructure for person-centered, self-directed supports that promote self-determination. The opportunity to live self-determined lives has been identified as a right of people with disabilities in federal policy, and enhanced self-determination has been identified as a key dimension of and predictive of individual quality of life across cultures (Lachapelle et al., 2005; Schalock, Bonham, & Verdugo, 2008; Schalock et al., 2005). Researchers have documented that self-determination status predicts valued life outcomes, including employment and community participation (Shogren & Shaw, in press; Shogren, Wehmeyer, Palmer, Rifenbark, & Little, 2015; Wehmeyer & Palmer, 2003; Wehmeyer & Schwartz, 1997). Researchers have also documented that supporting self-determination by teaching skills and creating opportunities for the expression of self-determination leads to enhanced self-determination (Algozzine, Browder, Karvonen, Test, & Wood, 2001; Wehmeyer et al., 2012). However, despite the sustained work by self-advocates as well as advances in research, people with intellectual and developmental disabilities continue to experience significant barriers to developing and expressing self-determination. These barriers include the following:

- Low expectations (Wehmeyer & Abery, 2013).
- Lack of societal understanding and adoption of social-ecological and person-environment fit models of disability (Schalock et al., 2010).
- Lack of opportunities for youth development, infrastructure development, and alternative funding streams in the self-advocacy movement (Caldwell, 2010).
- Lack of supports for leadership development in the self-advocacy movement (Caldwell, 2011).
- Lack of opportunities for direct involvement of self-advocates in research and in the implementation and evaluation of supports (Caldwell, 2010; McDonald & Raymaker, 2013).
Limited access to and research on technology supports to enhance self-determination (Brad-dock, Hoehl, Tanis, Ablowitz, & Haffer, 2013).

Limited means through which to demonstrate the impact of self-determination on outcomes and communicate these findings to the public and to policy-makers (Shogren et al., 2009.).

Lack of focus on the implementation of interventions and supports to promote self-determination at scale in organizations (e.g., schools, support provider organizations) and in communities (Bacon et al., 2011).

Limited measures to assess self-determination, especially among persons with the most extensive support needs (Shogren et al., in press).

Lack of focus on addressing contextual factors, including cultural factors in self-determination research (Shogren, 2011, 2013).

Developing the Goals

The National Goals 2015 conference provided an opportunity to bring together leaders in the intellectual and developmental disability field to summarize the current state of knowledge in the field and identify a platform of national goals in research, practice, and policy in IDD. The organizers identified ten topical areas of focus, including Self-Determination and Self-Advocacy which is the focus of this article. Each strand was charged with developing a platform of national goals for research over the next 10 years that have the most potential for impacting policy and practice.

To develop these research goals, the Self-Determination and Self-Advocacy Strand met as part of the 2015 National Goals conference over the course of two days, as well as heard presentations by federal agency leaders, leaders in the self-advocacy movement, and leading researchers. The co-authors of this article were members of the Self-Determination and Self-Advocacy Strand and are leaders in self-advocacy, research, policy, and practice related to self-determination and self-advocacy.

Before the conference, each member of the self-determination and self-advocacy strand was asked to think critically about (a) what we do not know (and need to know) about self-determination and self-advocacy; (b) what are the critical research questions that need to be answered to inform policy and practice for the next 10 years in the field; and (c) what are the critical implications for policy and practice of addressing these questions. The intended goal was to develop, during the 2 days of meetings, concrete recommendation and goals for national research that would have the greatest impact on policy and practice initiatives using these questions as a base.

During the discussions that occurred at the conference, the first day was developed to identify the most pressing current issues and controversies in the field related to self-determination and self-advocacy, with presentations from each strand member on their current work as well as more in-depth presentations on several issues identified as particularly salient to the future of self-determination and self-advocacy research including, the current status of the self-advocacy movement, efforts to promote supported decision-making to enhance self-determination, and issues of taking self-determination interventions and supports to scale. This discussion was used to shape a list of key needs related to the major challenges organized around the two foci of the strand, which were further defined during the discussion as collective self-advocacy and personal self-determination. Specifically, the major challenges related to collective self-advocacy focused on (a) ensuring that self-advocacy was understood as a movement; (b) developing structures to facilitate leadership, infrastructure, and independent funding for the movement; and (c) actively involving self-advocates as equal partners in research documenting the impact of the movement. Major challenges related to personal self-determination focused on the need to further develop the knowledge base of policy and practices that lead to enhanced skills, opportunities, and supports for self-determination. Specific problems included the need to (a) research ways that different types of supports impacted self-determination, specifically the impact of self-directed services and supported decision making on self-determination related outcomes, (b) assessment issues, (c) supporting people with extensive support needs, and (d) educating people that provide support across the lifespan (i.e., teachers, employers, direct service professionals, and family members).

After identifying the major challenges—or more specifically, answering the question of what we need to know to advance collective self-advocacy and personal self-determination—we
shifted to brainstorming directions for future research that would have the maximum impact on policy and practice to address the major challenges in the field. This discussion led to the following recommendations, jointly crafted by the coauthors of this article.

**Recommended Research Goals**

The Self-Determination and Self-Advocacy Strand identified seven broad goals for research over the next 10 years. These goals were identified as having the highest potential for impacting policy and practice in the intellectual and developmental disability field related to self-determination and self-advocacy. The first three goals relate to enhancing collective self-advocacy and the last four to enhancing personal self-determination. Each goal has subobjectives that further define necessary steps to move forward with testing solutions to address the major challenges described previously.

1. Identify, implement, and evaluate best practices in research that involve self-advocates in the research, planning, implementation, analysis, and dissemination phases.
   a. Explore methodologies that equalize the power dynamics in all phases of research;
   b. Promote self-advocate involvement in research review and RFA processes in federal and foundation research;
   c. Build leadership pipeline of self-advocates with research literacy, and hiring of self-advocates as researchers.

2. Identify and evaluate best practices to advance the financial independence and capacity of self-advocates and self-advocate-led organizations, with a focus on supporting self-advocacy organizations to build leadership, independent funding sources, and infrastructure.
   a. Establish and support a National Technical Assistance and Research Center on self-advocacy to identify, evaluate, and disseminate best practices to advance self-advocacy organizations and the self-advocacy movement, with the research led by self-advocates and housed within a national self-advocacy organization as the lead grantee.

3. Identify, implement, and evaluate best practices in using existing and emerging technologies to promote self-advocacy and the self-advocacy movement.
   a. Fund and implement research to evaluate universal design features that are most important to promoting cognitive access and self-determination.
   b. Engage in research to determine what policies promote greatest access to and use of technology to enhance self-determination.
   c. Engage in research on the most effective strategies to teach and support technology use to enhance self-determination.
   d. Build collaborative relationships with technology companies and developers to involve self-advocates in the research and development process and throughout the company.

4. Identify, implement and evaluate the most effective ways to build systems of supports based on individual preferences and support needs to enhance self-determination.
   a. Research the impact of supported decision-making on quality of decision-making and self-determination related outcomes when supports are linked to the preferences and support needs of people with intellectual and developmental disabilities.
   b. Identify critical factors at all levels of the ecosystem that support or serve as barriers to developing systems of supports that enhance the self-determination of people with intellectual and developmental disabilities.
   c. Undertake research with respect to approaches to take evidence-informed practices to support self-determination to scale across organizations (e.g., education systems, support provider organizations, employers, etc.).
   d. Evaluate the impact of self-directed supports on the exercise of self-determination, and build a continuum of self-directed supports.
   e. Conduct research on the impact of supporting people with disabilities in non-provider owned housing, on self-determination.

5. Research and develop strategies to measure self-determination at multiple levels across the lifespan that include people with intellectual and developmental disabilities.
a. Explore, in large scale evaluation systems, the addition of validated assessments of self-determination.
b. Develop ways to assess the self-determination of people with extensive support needs.
c. Promote the use of self-determination assessment data for individual decision-making and program evaluation across the lifespan (e.g., schools, home, community, work).
d. Undertake research with respect to critical environmental and contextual factors that impact self-determination.

6. Research and develop supports to enable people with extensive support needs to be self-determining.
   a. Research strategies to promote universal design of self-determination interventions to promote cognitive access and self-determination.
   b. Research strategies to support self-determination of people with emerging communication skills.

7. Identify, implement, and evaluate best practices to enable people who provide support across the lifespan (i.e., teachers, employers, direct service professionals (DSPs), family members) to understand and enhance opportunities for self-determination of people with intellectual and developmental disabilities in a culturally competent manner.
   a. Engage in research to develop and evaluate self-advocate-led training for people who provide support across the lifespan on enabling self-determination.
   b. Engage in research to support self-advocates to communicate their wants and needs, and express self-determination when interacting with people who provide support across the lifespan.
   c. Engage in research to determine what policies and practices promote opportunities for self-determination across all community environments (e.g., education, work, home).
   d. Engage in research on technology that supports the self-determination of people with intellectual and developmental disabilities and involves those that provide support across the lifespan.
   e. Engage in research on effective ways to scale-up self-determination interventions across the lifespan and all community environments (e.g., education, work, home).

**Implications**

The seven recommendations and associated subrecommendations provide direction for research in the intellectual and developmental disability field that have the potential to advance policy and practice related to self-determination and self-advocacy over the next 10 years. Despite significant progress led by the self-advocacy movement and supported by research on the impact of self-determination on positive life outcomes, substantial work is still needed to move the field forward and actualize the potential of the self-advocacy movement and the enhanced personal self-determination. These recommendations provide guidance for leaders in the self-advocacy movement, researchers, funding agencies, policymakers, and practitioners for key directions that must be emphasized to move the field forward and enable the conditions that support all people with intellectual and developmental disabilities to lead self-determined lives.

**References**


Received 8/27/2015, accepted 8/31/2015.

This article was produced in part under Grant Number 90RT5019 awarded by the U.S. Department of Health and Human Services, Administration on Community Living (ACL), National Institute on Disability, Independent Living, and Rehabilitation Research to
the Research and Training Center on Community Living and Employment at the University of Minnesota. The contents of this article do not necessarily reflect the policy of the ACL and should not be assumed to be endorsed by the U.S. Federal Government.

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