Self-Determination and People with Intellectual and Developmental Disabilities: What Does The Research Tell Us?

Institute for Human Development, University of Missouri Kansas City
Kansas University Center on Developmental Disabilities, University of Kansas
Center on Human Development, University of Oregon
Department of Disability and Human Development, University of Illinois Chicago
Westchester Institute for Human Development, New York Medical College
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There exists an already substantive and still growing literature base pertaining to self-determination and people with disabilities. The intent of this slide show is to provide a synthesis of major findings in the area of self-determination pertaining to youth and adults with intellectual and developmental disabilities.
What Does the Research Tell Us About Self-Determination?

• The findings in this slide show come from a comprehensive review of the literature on self-determination published in 2007 in the journal *Exceptionality,* as well as from a comprehensive review of the research published subsequent to this review.

• Studies included in the review met these selection criteria:
  - The researchers measured global self-determination, as opposed to one component (such as choice making or problem solving only), using a validated measure of self-determination. By measuring “global self-determination,” we mean that the research must have actually measured self-determination using a valid measure of self-determination.
  - The studies included in the review had to involve adults/students with disabilities.

What Does the Research Tell Us About Self-Determination? Caveats and Qualifiers

• This slide show is an attempt to synthesize information from an already large and constantly growing literature base. In essence, it hits the high points about what is known from research and provides representative citations.

• This synthesis focuses on issues of self-determination pertaining to youth/adults with intellectual and developmental disabilities, so does not constitute a synthesis of the literature in self-determination across disabilities.

• The intent of this presentation is to provide a foundation with regard to knowledge obtained through research so as to guide intervention development and implementation and the provision of supports to enable people with intellectual and developmental disabilities to become more self-determined.
Finding Summary: Self-Determination Status

• Research shows that youth/adults with disabilities are less self-determined than their non-disabled peers.
  – It is important, however, not to assume that this in any way reflects the capacity of people with disabilities to become self-determined. The research clearly shows that people with disabilities have many fewer opportunities to make choices and express preferences across their daily lives.
Representative Studies: Self-Determination Status


Finding Summary: Factors Contributing to Self-Determination

• Social abilities and adaptive behavior skills are related to more positive self-determination.

• Choice-making opportunity is a strong predictor of self-determination. Research shows that the environments in which adults with disabilities live or work limit opportunities to make choices and restrict personal autonomy.

• Although many people believe that people with intellectual disability cannot be self-determined because of their cognitive impairment, research consistently shows that while SD is positively correlated with IQ, that relationship is generally weak and IQ is not predictive of self-determination status.
  
  – IQ is predictive* of where one lives/works, which in turn is predictive of self-determination status by virtue of the above-noted findings.

*By predictive, we simply mean the research shows a statistical relationship between IQ and where one lives/works. This should not be interpreted to mean that IQ must, by any means, be predictive of where one lives or works; it is simply the case at the current time.
Representative Studies: Factors Contributing to Self-Determination


Representative Studies: Factors Contributing to Self-Determination (continued)


Finding Summary: Self-Determination and Adult Outcomes

- Multiple research studies find that a person’s self-determination status predicts higher quality of life.
- Self-determination status is positively correlated with more positive post-secondary outcomes, including employment, independent living, and community inclusion for youth with disabilities.
- Young adults who are more engaged in personally-valued recreation activities are more self-determined, suggesting a reciprocal relationship between recreation activities and self-determination.
Finding Summary: Self-Determination and Adult Outcomes (continued)

• Students with cognitive disabilities who leave school as self-determined young people:
  – Are more independent one year after graduation.
  – Are more likely to live somewhere other than where they lived in high school one year after graduation.
  – Are significantly more likely to be employed for pay at higher wages one year after graduation.
  – Are significantly more likely to be employed in a position that provides health care, sick leave, and vacation benefits three years after graduation.
  – Are significantly more likely to live independently three years after graduation.
Representative Studies: Self-Determination and Adult Outcomes


Representative Studies: Self-Determination and Adult Outcomes (continued)


Finding Summary: Perceptions of Self-Determination and People with Disabilities

- Adults with disabilities themselves rank self-determination as more important than do professionals and parents/family members.
- Special education teachers report that:
  - they are familiar with self-determination;
  - believe self-determination is an important component of transition planning;
  - believe that student involvement in planning is important;
  - their level of training, students’ type and level of disability, and type of teaching placement impact their ratings of the importance of promoting self-determination.
- Parents of school-age students with disabilities perceive promotion of self-determination as important.
  - Report that they do not believe that their sons/daughters receive enough instruction on component elements of self-determined behavior at school.
Representative Studies: Perceptions of Self-Determination and People with Disabilities


Finding Summary: Efforts to Promote Self-Determination

- Despite wide acceptance of the importance of self-determination, research has consistently found that explicit instruction to promote self-determination during the school years is limited, though more recent studies suggest that this situation may be changing.
  - Goals addressing self-determination are not included on many student’s Individualized Education Programs.
  - When efforts to promote self-determination are in place, there are few efforts to systematically assess the effect of those interventions.

- Teachers report that barriers to promoting self-determination include:
  - Their belief about whether the student will benefit;
  - Insufficient time, particularly in context of No Child Left Behind;
  - Insufficient training to and knowledge about promoting self-determination.
  - Insufficient time to plan to integrate instruction to promote self-determination into the instructional day.
Representative Studies: Efforts to Promote Self-Determination


Representative Studies: Efforts to Promote Self-Determination (continued)


Finding Summary: Efficacy of Interventions to Promote Self-Determination

• Data exists to support the efficacy of several self-determination-focused intervention models/programs, including:
  – Steps to Self-Determination (Hoffman & Field, 1995)
  – TAKE CHARGE for the Future (Powers et al., 2001)
  – Self-Determined Learning Model of Instruction (Wehmeyer, Palmer, Agran, Mithaug, & Martin, 2000)

• Meta-analytic (group and single-subject design studies) of existing research show that students with disabilities can acquire component elements of self-determined behavior (e.g., choice making, decision making, problem solving, goal setting and attainment, self-advocacy, self-regulation, perceptions of efficacy, self-awareness, self-knowledge) if taught.
  – Student-directed learning strategies particularly powerful.
Representative Studies: Efficacy of Interventions to Promote Self-Determination


Representative Studies: Efficacy of Interventions to Promote Self-Determination (continued)


Finding Summary: Student Involvement and Self-Determination

• Research has shown that students with disabilities are not major players in their IEP/transition planning meetings.
• Research has also shown that students with disabilities can learn the skills to be active participants in their IEP/transition planning meetings.
• Research suggests that student involvement has a reciprocal effect with self-determination. That is, students who are more self-determined are more likely to be involved in their educational planning, but getting students involved in their planning—indeed, independent of their level of self-determination—enhances self-determination.
Finding Summary: Student Involvement and Self-Determination (continued)

- Data exists to support the efficacy of the following student—involve ment related interventions/programs:
  - Next S.T.E.P. (Halpern, et al., 1997)
  - Self-Directed IEP (Martin, Huber Marshall, Maxon, & Jerman, 1997)
  - Self-Advocacy Strategy (VanReusen et al., 2002).
  - Whose Future is it Anyway? (Wehmeyer et al., 2005).
Representative Studies: Student Involvement and Self-Determination

