

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



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

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.

*Chambers, C.R., Wehmeyer, M.L., Saito, Y., Lida, K.M., Lee, Y., & Singh, V. (2007). Self-determination: What do we know? Where do we go? *Exceptionality*, 15, 3-15.



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.

A National Gateway to Self-Determination funded by the US Department of Health and Human Services, Administration on Developmental Disabilities

Representative Studies: Self-Determination Status

- Stancliffe, R. J., Abery B. H., & Smith, J. (2000). Personal control and the ecology of community living settings: Beyond living-unit size and type. *American Journal on Mental Retardation*, 105, 431-454.
- Wehmeyer, M. L., Kelchner, K., & Richards, S. (1996). Essential characteristics of self-determined behavior of individuals with mental retardation. *American Journal on Mental Retardation*, 100, 632-42.
- Wehmeyer, M. L., & Metzler, C. (1995). How self-determined are people with mental retardation? The National Consumer Survey. *Mental Retardation*, *33*, 111 119.



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 selfdetermination 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.



funded by the US Department of Health and Human Services, Administration on Developmental Disabilities

Representative Studies: Factors Contributing to Self-Determination

- Nota, L., Ferrrari, L., Soresi, S., & Wehmeyer, M.L. (2007). Self-determination, social abilities, and the quality of life of people with intellectual disabilities. *Journal of Intellectual Disability Research*, 51, 850-865.
- Shogren, K. A., Wehmeyer, M. L., Palmer, S. B., Soukup, J. H., Little, T. D., Garner, N. & Lawrence, M. (2007). Examining individual and ecological predictors of the self-determination of students with disabilities. *Exceptional Children*, 73, 488-509.
- Stancliffe, R. J. (2001). Living with support in the community: Predictors of choice and self-determination. *Mental Retardation and Developmental Disabilities Research Reviews*, 7, 91-98.
- Stancliffe, R. J., Abery B. H., & Smith, J. (2000). Personal control and the ecology of community living settings: Beyond living-unit size and type. *American Journal on Mental Retardation*, 105, 431-454.
- Stancliffe, R. & Wehmeyer, M. L. (1995). Variability in the availability of choice to adults with mental retardation. Journal of Vocational Rehabilitation 5 319-328



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

- Wehmeyer, M. L., Kelchner, K. & Richards, S. (1995). Individual and environmental factors related to the self-determination of adults with mental retardation. Journal of Vocational Rehabilitation, 5,291-305.
- Wehmeyer, M. L., & Bolding, N. (2001). Enhanced self-determination of adults with mental retardation as an outcome of moving to community-based work or living environments. Journal of Intellectual Disability Research, 45, 371-383.
- Wehmeyer, M. L., & Bolding, N. (1999). Self-determination across living and working environments: A matched-samples study of adults with mental retardation. Mental Retardation, 37, 353 363.



Finding Summary: Self-Determination and Adult Outcomes

- Multiple research studies find that a person's selfdetermination 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.



funded by the US Department of Health and Human Services, Administration on Developmental Disabilities

Representative Studies: Self-Determination and Adult Outcomes

- Copeland, S.R., & Hughes, C. (2002). Effects of goal setting on task performance of persons with mental retardation. *Education and Training in Mental Retardation and Developmental Disabilities*, 37, 40 54.
- Lachappelle Y., Wehmeyer M. L., Haelewyck M. C., Courbois Y., Keith K. D., Schalock R., Verdugo M. A., & Walsh P. N. (2005) The relationship between quality of life and self-determination: an international study. *Journal of Intellectual Disability Research* 49, 740-744.
- McGuire, J., & McDonnell, J. (2008). Relationships between recreation and levels of self-determination for adolescents and young adults with disabilities. *Career Development for Exceptional Individuals*, 31(3), 154-163.
- Sowers, J., & Powers, L. (1995). Enhancing the participation and independence of students with severe physical and multiple disabilities in performing community activities. *Mental Retardation*, 33, 209 220.



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

- 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, 131-144.
- Wehmeyer, M. L. & Schwartz, M. (1997). Self-determination and positive adult outcomes: A follow-up study of youth with mental retardation or learning disabilities. *Exceptional Children*, 63, 245-255.
- Wehmeyer, M. L. & Schwartz, M. (1998). The relationship between self-determination and quality of life for adults with mental retardation. *Education and Training in Mental Retardation and Developmental Disabilities*, 33, 3-12.



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 selfdetermination.
- 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.



funded by the US Department of Health and Human Services, Administration on Developmental Disabilities

Representative Studies: Perceptions of Self-Determination and People with Disabilities

- Agran, M., Snow, K., & Swaner, J. (1999). Teacher perceptions of self-determination: Benefits, characteristics, strategies. *Education and Training in Mental Retardation on Developmental Disabilities*, 34, 293-301.
- Schalock, R., Verdugo, M., Jenaro, C., Wang, M., Wehmeyer, M., Xu, J., & Lachapelle, Y. (2005). Cross-cultural study of core quality of life indicators. *American Journal on Mental Retardation*, 110, 298-311.
- Thoma, C. A., Nathanson, R., & Baker, S. R. (2002). Self-determination: What do special educators know and where do they learn it? *Remedial and Special Education*, 23, 242-247.
- Wehmeyer, M. L., Agran, M. & Hughes, C. (2000). A national survey of teachers' promotion of self-determination and student directed learning. *Journal of Special Education*, *34*, 58-68.
- Grigal, M., Neubert, D.A., Moon, M.S., & Graham, S. (2003). Self-determination for students with disabilities: views of parents and teachers. *Exceptional Children*, 70, 97-112.



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.



funded by the US Department of Health and Human Services, Administration on Developmental Disabilities

Representative Studies: Efforts to Promote Self-Determination

- Carter, E.W., Lane, K.L., Pierson, M.R., & Stang, K.K. (2008). Promoting self-determination for transition-age youth: Views fo high school general and special educators. Exceptional Children, 75(1), 55-70.
- Eisenman, L.T., & Chamberlin, M. (2001). Implementing self-determination activities: Lessons from schools. *Remedial and Special Education*, 22(3), 138-147.
- Millar, D.S. (2008). Self-determination in relation to having or not having a legal guardian: Case studies of two school-aged young adults with developmental disabilities. *Education and Training in Developmental Disabilities*, 43(3), 279-273.
- Sands, D., Spencer, K., Gliner, J., & Swaim, R. (1999). Structural equation modeling of student involvement in transition-related actions: The path of least resistance. *Focus on Autism and Other Developmental Disabilities*, 14, 17 27.



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

- Thoma, C.A., Pannozzo, G.M., Fritton, S.C., & Bartholomew, C.C. (2008). A qualitative study of preservice teachers' understanding of self-determination for students with significant disabilities. *Career Development for Exceptional Individuals*, 31, 94-105.
- Wehmeyer, M. L., Agran, M. & Hughes, C. (2000). A national survey of teachers' promotion of self-determination and student directed learning. *Journal of Special Education*, *34*, 58-68.
- Wehmeyer, M. L., & Schwartz, M. (1998). The self-determination focus of transition goals for students with mental retardation. *Career Development for Exceptional Individuals*, 21, 75 86.
- Zhang, D., Katsiyannis, A., & Zhang, J. (2002). Teacher and parent practice on fostering self-determination of high school students with mild disabilities. *Career Development for Exceptional Individuals*, 25, 157-169.



funded by the US Department of Health and Human Services, Administration on Developmental Disabilities

Finding Summary: Efficacy of Interventions to Promote Self-Determination

- Data exists to support the efficacy of several selfdetermination-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 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.



funded by the US Department of Health and Human Services, Administration on Developmental Disabilities

Representative Studies: Efficacy of Interventions to Promote Self-Determination

- Agran, M., Blanchard, C., & Wehmeyer, M. L. (2000). Promoting transition goals and self-determination through student-directed learning: The Self-Determined Learning Model of Instruction. *Education and Training in Mental Retardation and Developmental Disabilities*, 35, 351 364
- Algozzine, B., Browder, D., Karvonen, M., Test, D.W., & Wood, W.M. (2001). Effects of intervention to promote self-determination for individuals with disabilities. *Review of Educational Research*, 71, 219 277.
- Bambera, L.M., & Gomez, O.N. (2001). Using a self-instructional training package to teach complex problem-solving skills to adults with moderate and severe disabilities. *Education and Training in Mental Retardation and Developmental Disabilities*, 36, 386-400.
- Browder, D., Wood, W. M., Test, D. T., Algozzine, B. & Karvonen, M. (2001). A map for teachers to follow in reviewing resources on self-determination. *Remedial and Special Education*, 22, 233-244.
- Field, S., & Hoffman, A. (2002). Lessons learned from implementing the Steps to Self-Determination curriculum. Remedial and Special Education, 23(2), 90-98.
- Hoffman, A., & Field, S. (1995). Promoting self-determination through effective curriculum development. *Intervention in School and Clinic*, 30(3), 134-141.



funded by the US Department of Health and Human Services, Administration on Developmental Disabilities

Representative Studies: Efficacy of Interventions to Promote Self-Determination

(continued)

- Powers, L.E., Turner, A., Westwood, D., Matuszewski, J., Wilson, R., & Phillips, A. (2001). A controlled field-test of Take Charge: A multi-component intervention to promote adolescent self-determination. *Career Development for Exceptional Individuals*, 24, 89-104.
- Powers, L.E., Ellison, R., Matuszewski, J., and Turner, A. (2004). *TAKE CHARGE for the future*. Portland, OR: Portland State University Regional Resource Center.
- Test, D.W., Fowler, C., Brewer, D., & Wood, W. (2005). A content and methodological review of self-advocacy intervention studies. *Exceptional Children*, 72, 101-125.
- Wehmeyer, M. L., Palmer, S., Agran, M., Mithaug, D., & Martin, J. (2000). Promoting causal agency: The Self-Determined Learning Model of Instruction. *Exceptional Children*, 66, 439 453



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—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—involvement 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).

funded by the US Department of Health and Human Services, Administration on Developmental Disabilities

Representative Studies: Student Involvement and Self-Determination

Allen, S.K., Smith, A.C., Test, D.W., Flowers, C., & Wood, W.M. (2001). The effects of Self-Directed IEP on student participation in IEP meetings. *Career Development for Exceptional Individuals*, 24, 107-120.

Arndt, S.A., Moira, K., & Test, D.W. (2006). Effects of the Self-Directed IEP on student participation in planning meetings. *Remedial and Special Education*, 27(4), 194-207.

Halpern, A.S., Herr, C.M., Wolf, N.K., Doren, B., Johnson, M.D., & Lawson, J.D. (1997). *Next S.T.E.P.: Student Transition and Educational Planning*. Austin, TX: Pro-ED.