

Self-Determination and Choice

Michael L. Wehmeyer and Brian H. Abery

Abstract

Promoting self-determination and choice opportunities for people with intellectual and developmental disabilities has become best practice in the field. This article reviews the research and development activities conducted by the authors over the past several decades and provides a synthesis of the knowledge in the field pertaining to efforts to promote self-determination and choice.

Schalock and Verdugo (2002, 2012) have identified self-determination as a core dimension of quality of life, and over the past two decades, efforts to promote self-determination have been associated with more positive school, community, and adult outcomes for people with intellectual and developmental disabilities (IDD) (Wehmeyer, Abery, Mithaug, & Stancliffe, 2003; Wehmeyer et al., 2007). Further, choice opportunity and self-determination have become part of the demands by people with disabilities in the self-advocacy movement and these ideas have been incorporated into the disability rights and empowerment movement (Wehmeyer, 2004, 2011, 2013a). Clearly, efforts to promote community inclusion and quality of life need to include efforts to promote and support self-determination. This paper will examine the state of the field with regard to self-determination and people with IDD.

What is Self-Determination?

Self-determination is a general psychological construct within the organizing structure of theories of human agentic behavior. An agentic person is the “origin of his or her actions, has high aspirations, perseveres in the face of obstacles, sees more and varied options for action, learns from failures, and overall, [and] has a greater sense of well being” (Little, Hawley, Henrich, & Marsland, 2002, p. 390). Human agentic theories “share the meta-theoretical view that organismic aspirations drive human behaviors” (Little, Snyder, & Wehmeyer, 2006, p. 61). An organismic perspective views people as active contributors to, or *authors* of, their behavior, which is self-regulated and goal-directed *action*. Self-determined people are, in essence, actors in their own lives, rather than being acted upon.

Our understanding of self-determination draws from our respective theoretical frameworks, each of which has been developed and evaluated within disability-specific and culturally diverse contexts. Space limitations constrain the depth to which we can discuss each framework, so readers are referred to Wehmeyer et al. (2003) for more details.

A Functional Theory of Self-Determination

Wehmeyer (Wehmeyer, Kelchner, & Richards, 1996) proposed a functional theory of self-determination, so called because actions are viewed as self-determination based upon the function they serve for the individual, in which self-determination is viewed as a dispositional characteristic (enduring tendencies used to characterize and describe differences between people). Self-determined behavior refers to “volitional actions that enable one to act as the primary causal agent in one’s life and to maintain or improve one’s quality of life” (Wehmeyer, 2005, p. 117). *Causal agency* implies that it is the person who makes or causes things to happen in his or her life, that he or she acts with an eye toward causing an effect to accomplish a specific end or to cause or create change. Self-determined actions are identified by four essential characteristics: (1) the person acts *autonomously*; (2) the behavior is *self-regulated*; (3) the person initiates and responds to the event(s) in a *psychologically empowered* manner; and (4) the person acts in a *self-realizing* manner. The functional model sees self-determination as an integral part of the process of individuation and adolescent development. This model has been empirically validated (Shogren et al., 2008; Wehmeyer et al., 1996); operationalized by the development of an assessment

linked to the theory (Wehmeyer, 1996); served as the foundation for intervention development, particularly with regard to the development of the self-determined learning model of instruction and related efforts (Wehmeyer, Palmer, Agran, Mithaug, & Martin, 2000); and provided impetus for a variety of research activities (see Wehmeyer et al., 2007). Finally, the functional model conceptualizes self-determination within a person-environment interaction framework, so it is relevant to the social-ecological approach to intervention we propose.

An Ecological Model of Self-Determination

Abery and Stancliffe (1996) proposed an ecological model of self-determination that defines the self-determination construct as “a complex process, the ultimate goal of which is to achieve the level of personal control over one’s life that an individual desires within those areas the individual perceives as important” (p. 27). The ecological model views self-determination as driven by the intrinsic motivation of all people to be the primary determiner of their thoughts, feelings, and behavior. It may involve, but is not synonymous with, independence and autonomy. Rather, it entails the person determining in what contexts and to what extent each of these behaviors/attitudes will be manifested. Self-determination, accordingly, is the product of both the person and the environment—of the person using the skills, knowledge, and beliefs at his/her disposal to act on the environment with the goal of obtaining valued and desired outcomes. The ecological model was derived from Bronfenbrenner’s ecological perspective (1979, 1989), within which people develop and lead their lives is viewed as consisting of four levels: the *microsystem*, *mesosystem*, *exosystem*, and *macrosystem* (See Wehmeyer et al., 2003 for more detail). The ecological model has been empirically evaluated (Abery, McGrew, & Smith, 1994; Abery, Simunds, & Cady, 2006; Stancliffe, Abery, & Smith, 2000), operationalized in the development of assessments (Abery, Simunds, & Cady, 2002; Abery, Stancliffe, Smith, McGrew, & Eggebeen, 1995a, 1995b), and has also provided a foundation for intervention (Abery, Arndt, et al., 1994; Abery & Eggebeen, 1995) and research (Abery et al., 2006).

What are the Research Findings?

There is, now, a literature base establishing the importance of promoting self-determination to

achieve more positive quality of life and community inclusion for people with intellectual and developmental disabilities. In the following sections, we present a brief synthesis of the knowledge base pertaining to what research suggests about the self-determination of people with intellectual and developmental disabilities and the importance of self-determination to their lives. We must emphasize that we have limited our synthesis to, in large measure, our own work and, more importantly, to research that has attempted to directly measure the global self-determination of people with intellectual and developmental disabilities. We begin by examining findings related to the self-determination status of people with IDD.

Research Shows that Youth/Adults with IDD are Less Self-Determined than Their Nondisabled Peers

When, in the early 1990s, efforts first began to emerge focused on promoting self-determination, it was important to establish the relative importance of self-determination to the lives of people with IDD. The first step in such an agenda is to identify if there really was a problem; that is, were people with IDD already self-determined? If the answer was yes, then there was probably no need to invest a lot in research and model development in this area. Of course, the hypothesis was the opposite; people with IDD were less self-determined than their nondisabled peers. Demographic data, follow-up data, and regression analyses conducted during this time (and subsequently) confirmed this to be the case (Stancliffe et al., 2000; Wehmeyer et al., 1996; Wehmeyer & Meltzer, 1995). An important point to made with regard to this finding, as borne out by subsequent research, was that this finding in no way speaks to the capacity of people with intellectual and developmental disabilities to become more self-determined. The literature clearly shows, for example, that people with intellectual and developmental disabilities have far fewer opportunities to make choices and express preferences in their lives (Stancliffe, 2001; Stancliffe et al., 2000; Stancliffe & Wehmeyer, 1995) and that many people with IDD who have the capacity to exercise control over their lives remain under substitute decision-making arrangements that tend to be permanent and often all too encompassing (Stancliffe, Abery, Springborg, & Elkin, 2000). We will return to the importance of choice in

self-determination subsequently, but stating that youth and adults with intellectual and developmental disabilities are less self-determined than their nondisabled peers as a research fact necessitates a statement with regard to the potential for people with IDD to become self-determined.

Research Shows that Youth/Adults with IDD can Become More Self-Determined if Given Adequate Supports

That this is the case has been demonstrated in multiple ways. Recent research implementing randomized-trial control group studies has established causal evidence that adolescents with IDD provided instruction to promote self-determination do become more self-determined (Palmer, Wehmeyer, Shogren, Williams-Diehm, & Soukup, 2012; Powers et al., 2012; Shogren, Palmer, Wehmeyer, Williams-Diehm, & Little, 2012; Wehmeyer, Palmer, Shogren, Williams-Diehm, & Soukup, 2013). Further, Algozzine, Browder, Karvonen, Test, and Wood (2001) conducted group- and single-subject design meta-analyses of studies in which students with disabilities had received some intervention to promote component elements of self-determined behavior, specifically, choice-making skills, decision-making skills, goal setting and attainment skills, self-advocacy knowledge or skills, problem-solving skills, and self-awareness skills. The group meta-analysis showed such instruction to have a moderate effect, while the single-subject design meta-analysis showed such interventions had a strong effect. Cobb, Lehmann, Newman-Gonchar, and Alwell (2009) conducted a narrative metasynthesis—a narrative synthesis of multiple meta-analytic studies—covering seven existing meta-analyses examining self-determination and concluded that there is sufficient evidence to support interventions to teach or promote choice-making, problem-solving, decision-making, goal setting and attainment, and self-advocacy skills as effective practices to promote self-determination.

Other research, mainly correlational and regression analytic studies have shown that the places in which people with IDD work or live have an impact on self-determination and that community-based non-congregate settings improve choice opportunity and self-determination (Stancliffe, 2001; Stancliffe et al., 2000; Wehmeyer & Bolding, 1999, 2001). Within community-living settings, Abery, Tichá, Smith, Welshons, and Berlin (2013)

found that adults with IDD engaged in significantly greater choice and decision making in those homes in which residential staff viewed the role of supporting self-determination as a critical aspect of their position and training such staff to ask a simple set of questions that provided opportunities for self-determination led to subsequent increases in this behavior on the part of residents. These issues of environmental (such as choice opportunity) and intra-individual (such as capacity to acquire skills, personality variables) correlates to or predictors of self-determination became an important focus in research that was beginning to look at the development of interventions and provision of supports.

Research Shows that Environmental and Intra-Individual Factors Contribute to or Predict the Self-Determination of People with IDD

There are a host of factors, both external and internal to the person, that have the potential to either enhance or limit self-determination. Within-person variables clearly play a role in the development of self-determination. Studies utilizing regression analysis have found, for example, that people with IDD who possess more well developed social abilities and adaptive behavior and engage in lower levels of maladaptive behavior exercise higher levels of self-determination (Abery & Ticha, 2012; Nota, Ferrari, Soresi, & Wehmeyer, 2007; Perry & Felce, 2005; Stancliffe et al., 2000). For adults with IDD, age does not predict self-determination status (Wehmeyer & Garner, 2003), though during adolescence, there is a consistent trend for higher self-determination as a function of increased age (Wehmeyer, 1996).

Finally, with regard to within-individual factors, there has been a consistent relationship between self-determination and intelligence level, as measured by IQ scores. Stancliffe et al. (2000) found that study participants with mild intellectual disabilities had higher self-determination scale scores. Wehmeyer (et al.) have found a generally consistent, statistically significant relationship between measured self-determination and IQ scores (Nota et al., 2007). In a large sample of people with intellectual and developmental disabilities, for example, Wehmeyer and Garner (2003) found a correlation of $r = .15$ between self-determination scores and IQ scores.

The relationship between self-determination and intelligence is, however, complex. Wehmeyer and Garner (2003) conducted a discriminant function analysis of predictors for self-determination scores for individuals with IDD and found that only choice opportunity (from among four variables, including IQ score) predicted membership in a high self-determination group. Similarly, a discriminant function analysis of autonomous functioning scores found everything but IQ scores as significant predictors, with higher perceptions of choice opportunity being the most powerful predictor.

The discriminant function analyses for living or work outcomes found, however, that level of IQ was the most significant contribution to more positive outcomes and for employment outcomes IQ was the only significant predictor. For living outcomes, both self-determination and autonomy also predicted more positive living outcomes. In other words, IQ level predicted where people would live or work, but were not predictors of whether they would be self-determined. Only choice opportunities predicted the latter, a point to which we will return momentarily. IQ scores are proxies for learning capacity, and there is evidence with adolescents with cognitive disabilities that capacity to self-determine is a predictive factor for overall self-determination (Shogren et al., 2007). What is important, most likely, is the capacity to learn new skills. That said, there is clear evidence that adolescents (Wehmeyer & Schwartz, 1998) as well as adults with IDD (Abery & Ticha, 2012) have significantly fewer opportunities to learn, practice, and refine personal capacities related to self-determination, so measures of capacity may be masking issues pertaining to opportunity. Further, Shogren et al. (2007) also found that the degree to which students were included was a predictor of more positive self-determination, so the environment in which one learns matters.

This leads us to the importance of environmental and contextual factors in self-determination. As noted, Wehmeyer and Garner (2003) showed, through a series of regression analyses, that choice opportunity was the strongest predictor of self-determination status of adults with IDD. This result was recently confirmed by Abery and Ticha (2012) using direct behavioral observation of the moment-to-moment interactions that occurred between support staff in small community residences and the adults with IDD whom they served.

Further, several studies have shown that the size and restrictiveness of living and work settings limits self-determination (Stancliffe et al., 2000; Stancliffe & Wehmeyer, 1995; Wehmeyer & Bolding, 1999, 2001; Wehmeyer, Kelchner, & Richards, 1995). Essentially, people who live and work in congregate settings, whether community based (e.g., group homes, sheltered workshops) or not (e.g., institutions, work activity centers) experience lower levels of self-determination. Wehmeyer and Bolding (1999, 2001) studied this using a matched samples design showing that this outcome was not related to IQ or age, but to characteristics of the setting itself. Stancliffe, Abery, et al. (Stancliffe, 1997, 2001; Stancliffe & Abery, 1997; Stancliffe et al., 2000) have shown, through multiple studies, that a key factor contributing to this outcome is that such settings, which typically have more paid staff and tend to be more heavily regulated and structured, limit choice opportunities significantly. Choice opportunity is easily measured, while other factors that are also probably in play are not... for example, it is likely that problems in congregate living and work settings are more often solved by paid staff, limiting the opportunity that the person with IDD has to learn and practice problem solving. The same is true for goal setting, decision making, and other components of self-determined behavior. There needs to be more research to tease out the impact of environment on these factors, but for now, it's clear that limitations in choice opportunity as a function of larger, congregate settings, serve as significant barriers to self-determination.

A similar set of factors typically present in residential settings may also be in play in schools and explain why Shogren et al. (2007) found that inclusive education opportunities promoted self-determination. At this time, however, there is insufficient research in those settings to state that definitively. Shogren et al. (2007) also found that knowledge about transition planning and transition goals predicted greater self-determination for adolescents with disabilities. Student involvement in educational and transition planning has been found to be related to self-determination status. Williams-Diehm, Wehmeyer, Palmer, Soukup, and Garner (2008) found a reciprocal relationship between such student involvement and self-determination (e.g., enhanced self-determination predicted greater student involvement, greater student involvement predicted higher self-determination).

Research Shows that Enhanced Self-Determination Results in More Positive School, Community, and Quality of Life Outcomes for People with IDD

Self-determination status has been linked, both correlationally and causally, to more positive school and adult outcomes. A number of studies have established a relationship (e.g., correlational evidence) between adolescent self-determination status at the time of graduation from high school and more positive employment, independent living, and community inclusion-related outcomes (Sower & Powers, 1995; Wehmeyer & Palmer, 2003; Wehmeyer & Schwartz, 1997). These studies found that students with IDD who left school as more self-determined achieved greater independence, higher rates of employment, and greater community living than did students with IDD who were not as self-determined. Recently, Wehmeyer et al. (2013) conducted a randomized trial control group study of the effect of multiple interventions to promote self-determination on the self-determination of high school students receiving special education services under the categorical areas of intellectual disability and learning disabilities. Students in the treatment group received instruction using a variety of instructional methods to promote self-determination and student involvement in educational planning meetings over 3 years—which will be detailed in a subsequent section—while students in the control group received no such intervention. The self-determination of each student was measured using two norm referenced instruments at baseline, after 2 years of intervention, and after 3 years of intervention. Analysis determined that students with cognitive disabilities who participated in interventions to promote self-determination showed significantly more positive patterns of growth in their self-determination scores than did students not exposed to interventions to promote self-determination.

Subsequently, in a follow-up study of the treatment and control group students from Wehmeyer et al. (2013), Shogren, Wehmeyer, Palmer, and Little (2012) investigated adult outcomes 1 and 2 years after leaving school. These researchers measured employment, community access, financial independence, independent living, and life satisfaction outcomes. Results indicated that self-determination status at the end of high school significantly predicted more positive employment,

career goal, and community access outcomes. Students who were self-determined were significantly higher in all of these areas. These two studies provided causal evidence that promoting self-determination results in enhanced self-determination, and that enhanced self-determination results in more positive adult outcomes, including employment and community inclusion.

Self-determination has been conceptually and correlationally linked to a more positive quality of life for adults with IDD. Wehmeyer and Schwartz (1998) studied the relationship between self-determination and quality of life for 50 adults with intellectual disabilities who lived in group homes and found that self-determination status predicted membership in a high quality of life group. Lachapelle et al. (2005) examined the relationship between self-determination and quality of life for 182 adults living in community settings in Canada, United States, Belgium, and France. Discriminant function analysis indicated that essential characteristics of self-determined behavior predicted membership in the high self-determination group and, overall, self-determination and quality of life were significantly correlated ($r = .49$).

Neely-Barnes (2005) examined the influence of choice opportunities and living arrangements on quality of life for 220 people with developmental disabilities. Using structural equation modeling, Neely-Barnes found that community-based living arrangements and greater opportunities to make choices were associated, and these two were, in turn, associated with greater quality of life.

Research Provides Efficacy Evidence for Interventions to Promote Self-Determination

Finally, data exist to support the efficacy of multiple interventions to promote student self-determination (Hoffman & Field, 1995; Powers et al., 2012; Shogren et al., 2012; Wehmeyer et al., 2012) as well as the self-determination of adults with IDD (Abery & Ticha, 2013). Further, data exists to support the efficacy of several student-involvement in educational planning interventions as having a positive effect on self-determination and student involvement (Martin et al., 2006; Palmer et al., 2012; Wehmeyer, Palmer, Lee, Williams-Diehm, & Shogren, 2011). Many of these studies involve single-case design or quasi-experimental studies, though several more recent

studies involve randomized trial control group studies.

Gaps in the Research

The research base on self-determination is skewed heavily toward school-based populations, in large measure because the U.S. Department of Education has funded research, model development, and outreach projects pertaining to self-determination for nearly 25 years. Initial funding focused almost exclusively on transition-age youth, almost instantly establishing a perspective among many funding agencies that self-determination was primarily an issue of adolescence and transition. As a result, to this day, research efforts focusing on this segment of the population have dwarfed those centering on preschool and elementary school-age children as well as adults. There still exist gaps, however, in the literature pertaining to schools, adolescents, and self-determination, and far too few evidence-based practices for use with this population. In addition, we still know relatively little about the critical role that parents play in fostering the development of self-determined children, and youth with IDD. Carter et al. (2013) have shown that the parents of children with IDD and autism rate a variety of skills associated with self-determination as important for their children to learn. Parents whose children did not experience intellectual disability or experienced mild IDD, however, rated these capacities as significantly more important than parents whose children had the most significant cognitive disabilities. In addition, although there have been efforts to develop strategies to assist parents to support the self-determination of their children with disabilities within the context of the home (e.g., Brotherson, Cook, Erwin, & Weigel, 2008; Weir, Cooney, Walter, Moss, & Carter, 2011) little research exists that has evaluated the impact of such programs/methods in a well-controlled manner.

Research is needed to explore variables that have an impact on self-determination, and in particular, the role of culture, ethnicity, linguistic diversity, and other factors as moderating variables that may potentially influence the impact of interventions (Wehmeyer, Abery, et al., 2011). Those few studies that have begun to explore cultural influences on the manner in which self-determination is conceptualized and expressed (e.g., Frankland, Turnbull, Wehmeyer, & Blackmountain, 2004; Leake & Boone, 2007) clearly

suggest that although there are some universal aspects to our conceptualizations of self-determination, ethnic and cultural belief systems must be understood and taken in to account when attempting to support enhanced outcomes in this area. Further, additional research needs to be undertaken within inclusive settings and on interventions to promote self-determination for all students, including those with IDD who receive their instruction in general education classrooms (Wehmeyer, 2013b).

The gaps in the knowledge base pertaining to how to best promote self-determination for adults with IDD are greater. Heller et al. (2011) identified a number of such gaps, noting that unlike intervention efforts with children and adolescents, efforts to promote the self-determination of adults with IDD need to be in the context of efforts to support them to achieve meaningful outcomes in their lives. Those areas of adult life in which Heller et al. found limited research with respect to the impact of self-determination include employment, independent living, health and wellness, aging, and post-secondary education.

Over the past decade, more and more adults with IDD have opted out of the formal residential service system and are living with their families rather than supported in community residential programs. At the current time, however, we know relatively little about the impact of this arrangement on opportunities for self-determination as well as its exercise. Over a decade ago, Seltzer and Krauss (2001) pointed out the absence of research literature on the degree of choice, personal autonomy, and self-determination of adults with IDD living with their families. They also alerted the field to the complexity of issues surrounding these types of living arrangements because as they state, “these are not just individual issues, but family issues, as each member living in the household balances and negotiates how their personal choices are expressed and respected and how their own goals and aspirations are meshed with or compete with those of other family members” (Seltzer & Krauss, 2001, p. 113). In spite of the movement from formal to informal support systems that has occurred over the past decade, little has been added to our understanding of issues related to adults with IDD living with their families. One thing that is clear, however, based on research which suggests that adults with IDD living at home are less likely to have opportunities to engage in preferred community activities than those supported through

the residential service system (Felce, Perry, & Kerr, 2011) is that we cannot assume that the mere fact of living with family increases opportunities to exercise self-determination.

Those gaps in the research noted above pale in comparison the lack of attention that has been given to better understanding the self-determination of persons with the most significant intellectual disability. In some of the seminal work in this area, Brown, Gothelf, Guess, and Lehr (1998) who defined self-determination for persons with the most significant intellectual disability as control over one's environment, described how preference assessments and positive behavior supports could be used to enhance outcomes in this area. In a case study, Singh et al. (2003) demonstrated the ability to teach a 14-year-old girl with multiple medical and physical disabilities as well as profound intellectual disability to make meal time choices through the use of microswitch technology. A comprehensive literature review of 21 intervention studies conducted by Wood, Fowler, Uphold, and Test (2005) showed that self-determination efforts with this segment of the IDD population have focused almost exclusively on choice making with investigators teaching only a narrow range of self-determination skills. As numerous researchers (e.g., Abery & Stancliffe, 2003; Wehmeyer, 2003) have argued, however, self-determination entails much more than merely making choices. At this time, those environmental factors that have an impact on opportunities for and the expression of self-determination among this segment of our population with disabilities is primarily conjecture. This group, who might best be conceptualized as "the forgotten ones" is in all likelihood composed of just those individuals who are in most need of self-determination supports.

The lack of attention that has been paid to research focused on the self-determination of children, youth, and adults with the most significant intellectual disabilities stems from a variety of factors including the belief among some individuals in the field that such persons are not capable of anything more than simple choice-making. As Abery and Ticha (2012) and Wehmeyer (2005) have argued, however, much of this stems from measurement limitations and the need to use proxy responders when individuals are not capable of understanding and responding to questions regarding the self-determination they exercise on their own.

Points of Contention and Debate

In general, there are few points of contention among professionals in the research pertaining to self-determination. There is general agreement with regard to the essential components that support self-determination and the importance of promoting it in the lives of children, youth, and adults with IDD. There has, however, been some confusion in the field stemming from both use of the term self-determination as synonymous with personal control and to refer to consumer-directed or controlled service systems.

Abery and Stancliffe (2003) point out in their tripartite, ecological model of self-determination few individuals' desire total personal control over many areas of life. More often, we wish to share control with those whom we trust. In addition, they argue that we do little to support self-determination when the only opportunities for control offered to persons with IDD are over areas of life they don't necessarily view as important. On this basis, they conceptualize self-determination as a highly individualistic construct that is decidedly different than personal control taking into consideration the degree of control a person desires to exercise over those areas of life that are important to them. This definition takes in to consideration the fact that cultural differences based on racial/ethnic group membership, sex, and family background are likely to exist in both the manner in which self-determination is conceptualized and expressed.

The second point of confusion stems from efforts that have focused on consumer-directed or controlled services systems. Such systems emphasize consumer and family control over budgets and how budgets are spent to provide supports for people with IDD. In many cases, and particularly in adult IDD systems, self-determination is understood only in that sense (e.g., consumer controlled services) (Wehmeyer, 1998, 2005). Clearly, innovative funding systems that emphasize consumer control will, almost certainly, lead to enhanced self-determination, so the need is to examine the impact of such systems on self-determination and quality of life.

A final point of debate relevant to self-determination is the recent contention of some individuals (e.g., Smith & Routel, 2010) that the construct has been misappropriated by the education and human service industries and rather than being used to enhance the quality of life experienced by persons with disabilities serves to keep them and

their families isolated. Employing a conflict theory approach, Smith and Routel (2010) contend that there is a lack of consensus in the field as to the meaning of self-determination and that this is a result of who currently controls and should control the definition. Citing efforts that have been undertaken by people with disabilities themselves, it is argued that self-determination means different things to different people and is “individually relative” for persons with disabilities and their families (Smith & Routel, 2010, p. 7) and a basic human right rather than a skill set or curriculum (Moseley, Gettings, & Cooper, 2005; O’Brien, 2000; Smith, 2006).

Although the state of affairs described by Smith and Routel (2010) might have accurately described the field at the time that efforts to better understand and support the self-determination were first initiated, it is our contention that we have moved far beyond this point today. The majority of conceptual frameworks currently available to better understand self-determination (e.g., the tripartite ecological theory of self-determination; Abery & Stancliffe, 2003; the functional theory of self-determination, Wehmeyer et al., 2003) are not the products of armchair philosophizing or individuals working within and for educational and human service systems. Rather, they were developed on the basis of intensive input from persons with disabilities and their family members. Operational definitions of self-determination (e.g., Abery & Stancliffe, 2003) have moved beyond simplistic versions that focused almost solely on choice making to take in to account cultural differences and the fact that different people desire to have differing amounts of personal control over specific areas of life that they view as important. Rather than serving to segregate and marginalize persons with disabilities, efforts undertaken in this area have focused on ensuring self-determination is viewed by all with the educational and service system as an inherent human right and that the goals, dreams, and visions of the future of individuals with disabilities are not only respected, but serve as the focal point for services and supports that are person centered in nature.

Emerging and Future Research

Although reductions in funding for basic research on self-determination may lead some to believe that there is no longer a need for work in this area, this could not be further from the truth. In general, the next generation of research questions with

respect to self-determination need to examine in more detail and with more specificity the impact of personal and ecological factors that influence its development, the efficacy of interventions, and the manner in which these variables affect self-determination among traditionally underrepresented groups including preschool age children, persons with the most significant intellectual disabilities, and those who are members of a variety of cultural groups.

There remains a need to develop better measures of global self-determination that can be used with children, youth, and adults with and without disability so as to be able to better integrate practice in the area in typical school, family, and community activities. There is a need, however, to move beyond our single-minded focus on assessing the *perceptions* of people with respect to their self-determination (i.e., how self-determined does a person indicate that they are when responding to interview or survey questions) to developing valid and reliable approaches to actually observe the exercise of self-determination and those actions on the part of others that either facilitate or serve as barriers to it. This will serve to both enhance the validity of our assessments as well as open up research and interventions in this area to persons with the most significant intellectual disabilities as well as the youngest children without the need to rely of proxy responses of dubious reliability and validity. As part of this paradigm shift, future research will need to better account for the fact that, in the large majority of cases, self-determination is exercised within the context of relationships (with people, organizations, systems, etc.) and that as a result, relationship factors need to be taken in to account. This conceptualization of self-determination being exercised within the context of relationships must also take in to consideration how the ecological context (home, community, school, work, etc.) influences such relationships and thereby opportunities for and the exercise of self-determination. In addition, research on self-determination will need to be undertaken within those contexts within which more and more persons with intellectual disabilities are spending their lives including inclusive educational and community environments, independent living, and/or with biological or foster families.

Interventions designed to enhance self-determination need to be examined with respect to the specific conditions under which they work best, and

with regard to their impact on meaningful outcomes in the lives of people with IDD, including employment, independent living, and so forth. Clearly, there is a need to engage in research that establishes evidence-based practices for use with adults with IDD that is culturally sensitive and promotes greater independence and inclusion in the community. As part of that effort, we need to move beyond conceptualizing intervention efforts as designed to “change” persons with disabilities (i.e., enhance skill development) and develop strategies and programs that have the potential to change the environment in such a way that more opportunities for self-determination and supports for its exercise are available. Abery, Tichá, Smith, Welshons, and Berlin (2013), for example, have found that the specific roles that direct service staff perceive as most important for themselves to fill in supporting persons with IDD is directly related to the number of opportunities these staff provide consumers for self-determination which in turn has an impact on the extent to which consumers exercise self-determination. As the late self-advocate Irving Martin (Personal Communication, 1999) once stated, “society needs to respect the rights of individuals (with intellectual disabilities) to chase our dreams and live our lives the way we want to rather than in the manner that other people expect us to.” It is also now the time to rid ourselves of the notion that one size fits all when we think about strategies and programs that have the goal of supporting self-determination. Behavior on the part of a parent, teacher, or staff person that serves to facilitate self-determination with one child, youth, or adult may have no impact or the opposite effect on another. If we accept the contention of Smith and Routel (2010) that the construct of interest is highly individualistic then we must also accept the challenge that supporting it may need to be approached in a highly individualized manner.

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Authors:

Michael L. Wehmeyer (email: wehmeyer@ku.edu), Beach Center on Disability, University of Kansas, 1200 Sunnyside Ave., 3101 Haworth Hall, Lawrence, KS 66045-7601; **Brian H. Abery**, University of Minnesota.

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