



A National Gateway to Self-Determination

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A Series of Papers on Scaling-Up Efforts to Promote Self-Determination

Paper 2: Personal Self-Determination and Moderating Variables that Impact Efforts to Promote Self-Determination

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The National Gateway to Self-Determination

The National Gateway to Self-Determination (SD) is a consortium of University Centers for Excellence in Developmental Disabilities (Missouri, Kansas, Oregon, New York, Illinois) in partnership with a National Self-Determination Alliance (including self-advocates, families, and numerous national partners). The overall goal of this project is **“to establish a sustainable, evidence-based training system that enhances self-determination training programs that lead to quality of life outcomes for individuals with developmental disabilities throughout the lifespan.”**

There are a number of important beliefs upon which this SD initiative is founded. They include:

- SD is best considered in the context of a **social-ecological framework**
- Development of SD is a **lifelong process**
- Scaling-up SD training activities must occur within an **evidence-driven** framework
- The development of SD is a means to obtaining an **improved quality of life**
- People with developmental disabilities **must be equal partners**

The purpose of this series of papers is to fill existing gaps in the SD literature related to these beliefs. For more resources on self-determination, please visit the National Gateway to Self-Determination website: www.aucd.org/ngsd.

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Previously, we introduced a social ecological approach to promote self-determination and mediating variables that impact such interventions. The purposes of this article are to provide detail with regard to how we understand the self-determination construct and to discuss moderating variables and how such variables impact the design and implementation of interventions to promote self-determination.

What Is Self-Determination?

Our understanding of self-determination draws from three 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, Abery, Mithaug, and Stancliffe (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, 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, Agran, Hughes, Martin, Mithaug, & Palmer, 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 colleagues (Abery & 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 et al., 1994; Abery & Eggebeen, 1995) and research (Abery et al., 2006).

Self-Determination as Self-Regulation

Mithaug (Wehmeyer, et al., 2003) hypothesized that self-determination is an unusually effective form of self-regulation markedly free of external influence in which people who are self-determined regulate their choices and actions more successfully than others. Mithaug suggested that individuals are often in flux between existing *states* and *goal* or desired states.

When a discrepancy between what one has and wants exists, an incentive for self-regulation and action becomes operative. With the realization that a discrepancy exists, the person may set out to achieve the goal or desired state. The ability to set appropriate expectations is based on the person's success in matching his or her *capacity* with present *opportunity*. Capacity is the person's assessment of existing resources (e.g., skills, interests, motivation), and opportunity refers to aspects of the situation that allow the individual to achieve the desired gain. Mithaug referred to optimal prospects as "just-right" matches in which people are able to correctly match their capacity (i.e., skills, interests) with existing opportunities (e.g., potential jobs). The experience generated during self-regulation is a function of repeated interaction between capacity and opportunity. Mithaug (1998) suggested that "self-determination always occurs in a social context" (p. 42) and that the social nature of the construct is worth reviewing because the distinction between self-determination and other-determination is "nearly always in play when assessing an individual's prospects for controlling their life in a particular situation" (p. 42).

Moderating Variables that Impact Self-Determination

It is important to note that self-determination as a *psychological construct* means the same thing for every person, whether that person does or does not have a disability; is of one particular race or ethnicity or another; is male or female; or lives in Quebec, Queensland, or Qatar. How the construct is operationalized—that is what is considered "self-determined

behavior,”—varies widely according to contextual variables, but the fact that self-determination *as a psychological construct* refers to self- (vs. other-) caused action to people acting volitionally, based upon their own will, does not vary. It then becomes critical to consider the moderating variables that describe differences in this operationalization when considering the design of interventions to promote self-determination.

Hinshaw (2007) defined moderator variables as “baseline factors that define subgroups with greater vs. lesser intervention response” (p. 1). The distinction between moderator and mediator variables is that moderator variables refer to characteristics of a *treatment sample* that may influence intervention outcomes while mediator variables refer to *processes occurring during treatment* that explain how and why the intervention is exerting its effects (p. 2). The first paper in this series discussed mediator variables in efforts to promote self-determination. The remainder of this paper will identify moderator variables that impact efforts to promote self-determination.

Culture as a Moderating Variable in Efforts to Promote Self-Determination

Culture provides the lens through which we view, interpret, and find meaning in the world in which we live. Culture structures perceptions, shapes behaviors, and defines our sense of reality. It also defines and determines the manner in which we recognize, understand, and accept disability (Goode & Maloof, in press). Culture is the learned and shared knowledge that specific groups use to

generate their behavior and interpret their experience of the world. It comprises beliefs about reality, how people should interact with each other, what they “know” about the world, and how they should respond to the social and material environments in which they find themselves. It is reflected in their religions, morals, customs, technologies, and survival strategies; it affects how they work, parent, love, marry, and understand health, mental health, wellness, illness, disability, and death. [Readers can also see a review of cultural competence conceptual frameworks in Balcazar, Suarez-Balcazar, Willis, and Alvarado (2010).]

Many members of minority or culturally diverse groups will recognize the general ideas behind the construct of self-determination as related to struggles for equity, equality, and empowerment. In the last century, the most prevalent use of the term self-determination has been in a political context, referring to the rights of people of a given country to determine their own political status and to self-governance, and, subsequently, by groups of people defined by features other than geographic boundaries who adopted the theme of the right to self-determination regarding self-governance as a principal theme of their civil rights and empowerment movements. For example, one principle of the celebration of Kwanzaa, observed in the United States to honor African-American heritage, is Kujichagulia, which translated means self-determination and refers to the principle of self-rule and self-governance as it expresses and supports the practice of Afrocentrism (the emphasis of the importance of African people in culture, philosophy, and history)

in the context of the American civil rights movement (Robinson, 2002).

It is not surprising, then, that the disability rights and advocacy movement would identify the right to self-determination as among the central tenets of its struggle for equal rights. In this context, self-determination is a means to empowerment, a term associated with a social movement and typically used in reference to actions that "enhance the possibilities for people to control their lives" (Rappaport, 1981, p. 15). Robert Williams, a leader in the disability self-advocacy movement and former commissioner of the Administration on Developmental Disabilities, effectively captured this link between self-determination and empowerment, stating:

But, without being afforded the right and opportunity to make choices in our lives, we will never obtain full, first class American citizenship. So we do not have to be told what self-determination means. We already know that it is just another word for freedom. We already know that self-determination is just another word for describing a life filled with rising expectations, dignity, responsibility, and opportunity. That it is just another word for having the chance to live the American Dream (Williams, 1989, p. 16).

For many people in the disability advocacy community the use of the term is a call for the universal (e.g., pertaining to a united group) right to independence and self-governance.

So, are there characteristics based upon culture that would influence the

outcome of interventions to promote self-determination (beyond the obvious that interventions should be delivered in the language the person uses)? If so, then there may be value in developing unique interventions to address those characteristics (as well as incorporating features addressing cultural relevance into any intervention). Cultures and contexts vary widely, not only as a function of the characteristics of the people within that culture but within specific cultural elements as well. As noted previously, such cultural elements impact the operationalization of the self-determination construct (e.g., what behaviors "express" self-determination) based upon, for example, how decisions are made or problems solved within that community. Frankland and colleagues (2004) concluded that the component elements of self-determined behavior proposed by the functional model of SD *were* relevant to Diné (Navajo) people, but that:

... the ways in which these are expressed differs from an Anglo perspective. While the Diné people value self-regulation and autonomy, they are operationalized more in an emphasis on the importance of interdependence and group cohesion above independence and autonomy. This examination of the application of self-determination within the Diné cultural context and traditions illustrates the universality of certain aspects of self-determination while at the same time indicating a critical need for educational services that reflect cultural, racial, and familial values of the student.

A clear difference among cultures that impacts the expression of self-determination is illustrated by the Diné nation's example of the degree to which cultures vary along a continuum ranging from collectivist to individualistic practices. Hall (1981) identified low-and high-context cultures, in which low-context cultures emphasize independence, the importance of the individual, and a future-time orientation. These cultures highly value individual rights and choice. High-context cultures value interdependence and relationships with others having a present-time orientation. Many interventions designed to promote self-determination have been developed and evaluated within cultures that emphasize individualism and autonomy. In many cultures though, as Hall suggested, a sense of self is understood in relationship(s) with and to others; individuals often set their goals considering both their own needs and family needs (e.g., bringing honor to the family). Turnbull and Turnbull (2001) listed contrasting beliefs, values, and practices between Anglo-European culture and other cultures, including personal control over the environment, individualism, self-help, competition, future orientation, and goal orientation (Turnbull & Turnbull, 2001; Zhang, 2006). Non-Western cultures may encourage values and behaviors that differ from those associated with the Western emphasis on individualism (Zhang, Wehmeyer, & Chen, 2005). The critical point to be made here is that efforts to promote self-determination must be culturally relevant and address efforts that promote self- (versus other) determination in ways that emphasize the values, beliefs,

and practices associated with the individuation process.

A good example of self-determination as being relevant across cultural contexts that vary on the individualistic /collectivist continuum was provided by Ewalt and Mokuau (1995) in a discussion about self-determination from the Pacific Islander perspective. They noted that "self-determination for the cultures of the Pacific region is defined by values of collective affiliation rather than by individualism" (p. 170). To illustrate the point, they provided the following vignette:

Debra, a Hawaiian woman, was interested in practicing medicine in the community in which she had recently completed her medical education. Here she was offered a physician's position with a reputable family clinic and a good salary. Combined with her comfortable living quarters and her network of friends, remaining in this community was an attractive option for Debra. However, her family, and in particular her parents, wished for Debra to establish her practice in the community in which she was raised. To do so would require her to move from the city back to her native community. Although there were a few moments of hesitation, Debra quickly adjusted and aligned her values with those of her family. She reasoned that by returning to her native community she would be reunited with her family and be available to provide medical care to members of her family and a community with severe health problems.

To people from more individually oriented cultures, Debra's chosen option might appear to "limit" her self-determination: she was acceding to the wishes of her parents and going from a context in which she had a lot of personal freedom to one where she would be subject to the rules governing a society in which she would have, at a minimum, less personal control over decisions that affect her life. In fact, such an analysis misses the point of self-determined behavior; it is not if one is acting independently, making one's own decisions, solving one's own problems, but rather whether or not one is the causal agent in one's life. Goode and Maloof (in press) noted that for people in high-context cultures that value social interdependence rather than individual independence, the concept of autonomy may feel incompatible with their world view and conflict with traditional beliefs and practices. Decisions for individuals are made taking into consideration the interests of the larger group (extended family or community) as well as the individual. Simultaneously, each—the larger group and the individual—has mutual responsibilities and provides support to one another. If a culture values a family-centered rather than an individual-centered model of decision-making, then expecting a person to make such decisions on his own will not feel empowering, but instead, runs the risk of making the person feel isolated and burdened.

Frankland and colleagues (2004) identified cultural structural factors that influence how self-determination is operationalized in different contexts, using as an example the factors that influence how the construct is operationalized among the Diné people.

- **Resident patterns:** Over half of Diné people live in small reservation towns while the rest live in remote areas of the reservation in small camps on land that has been passed down matrilineally. Because losing land is equated with loss of life and security, Diné people in rural areas make concerted efforts to retain their land, despite the poverty and unemployment that may be present in such remote areas. Decisions about where to live, then, which might seem illogical to someone outside the Diné nation, are driven by cultural factors in the operationalization of self-determination; that is, people choose to stay on long-held family land because of the cultural context and, in so doing, act in a self-determined manner.
- **Socioeconomic status:** Diné perspectives regarding financial stability are different from those held by Anglo-Europeans. For example, many Diné base their financial well-being upon (a) having reliable shelter, (b) a vehicle for transportation, (c) sufficient livestock for personal consumption and sale, and (d) a dependable, united family. The cultural emphasis on collective well-being (united family) becomes a way of life in which one's self-determination is operationalized.
- **Family structure:** Diné culture is organized by: (a) immediate family and (b) extended family or clans. Immediate family members are related by blood and members are

assigned or assume specific roles to perpetuate the family's survival and support, such as responsibility to care for livestock, tend area farms, care for the home, or provide assistance for the elderly. Extended family includes both distant blood-related relatives and distant non-blood related members, traced by a clan structure. Diné clan structure provides a foundation for ethics that guide social interactions, status, and responsibilities within one's tribe and in the community and provides a mechanism for uniting the Diné people regardless of blood lineage, thus serving to strengthen the identity of the Diné people as a family and as a tribe. It becomes obvious that the preference to remain within the Diné cultural context will require acceptance of a more prescribed role within society, including the types of jobs one does, as well as providing rules for governance, both personal and tribal.

Frankland et al. identified other factors that provide the context for the operationalization of self-determination in the Diné nation, including acculturation factors, different (from Anglo communities, at least) conceptualizations of child development and child roles, and differing perceptions of disability. These factors all impact what a "self-determined person" would look and act like in the Diné nation's cultural context

Ewalt and Mokuau (1995) identified similar factors for the operationalization of self-determination in a Pacific Island perspective. They include: (a) values for

collective affiliation and the affiliative nature of relationships; (b) an emphasis on cooperation rather than individual achievement; (c) the emphasis on the unity of the group by defined assignments for each member of the family; and (d) the emphasis of the family as the focal point, not the individual.

Yet another such factor, *parenting style*, emerges from cross-cultural research on children's development of self-determination. Great variations exist among cultures regarding parental practices. For example, Chinese parents are often characterized as authoritarian and controlling in parenting (Chao, 1996; Chen, Wang, Chen, & Liu, 2002), compared to their North American counterparts, and tend to emphasize children's respect for and listening to parents and other older relatives (Chen et al., 2002). It is inappropriate, though, to talk about these behaviors as facilitating or limiting self-determination in that what is "self-determined" in that context probably varies as much as parenting styles.

So, in conclusion, it is critical that efforts to promote self-determination take into account and are responsive to the structural and contextual factors that exist within cultures; otherwise such interventions run the risk of being irrelevant. We know far too little about the complex issues pertaining to culture and self-determination, and it will be incumbent upon anyone developing, evaluating, and implementing interventions to be cognizant of the unique strengths and characteristics of cultures that might have an impact on the intervention and to design such interventions in ways that support instead of hinder the development of self-

determination.

Other Moderating Variables in Efforts to Promote Self-Determination

Culture is but one moderating variable that needs to be considered in decisions about interventions to promote self-determination. In addition, several other factors may be relevant.

Gender. Data describing differences in self-determination by gender are limited and findings mixed, so it is difficult to unequivocally state whether gender is or is not a moderating variable that should be considered. Studies vary as to whether gender is a significant predictor of self-determination status, but we would point out, either way, that gender as a moderating variable for interventions to promote self-determination is probably a proxy for the cultural issues pertaining to gender roles in given societies. Rousso and Wehmeyer (2000) argued that in most cultures and countries, gender and disability form a “double-jeopardy” for biases and differing expectations that may result in differences in self-determination. One explanation, then, for findings of higher scores on measures of self-determination for girls and young women with intellectual and developmental disabilities could be the expectations in the United States; whether these expectations are appropriate or not begs the point. It is the fact that they exist, that girls and young women perform more of the caregiving and domestic responsibilities for families and, as such, assume such responsibilities earlier in life.

Age and Life Stages. Another moderating factor involves age or life stage. In general, there is a developmental trend with level of self-determination increasing throughout adolescence, then levelling off during adulthood (Wehmeyer, 1996). Wehmeyer & Garner (2003) found that age did not predict self-determination status although age did predict membership in a high or low autonomy group, with older people more likely to be in the high autonomy group. Abery et al. (2006) found that people ages 60 and older desired to exercise significantly less control over health care decision-making than people in the 35-59 age group, who in turn desired less control than 21-34 year olds. At work here as well, though, are life experiences. People with intellectual and developmental disabilities may vary widely based upon the opportunities they have had that lead them to be more (or less) self-determined. However, age may not be as good a predictor for what the intervention needs to promote although it must be a factor for how that intervention is designed. Adults with intellectual and developmental disabilities should not be relegated to such roles as student or perpetual children and must be treated as adults. Thus, interventions to promote self-determination for adults should be maximally self-directed and age and life-stage appropriate.

Cognitive Ability. A common assumption with regard to people with intellectual and developmental disabilities is that limitations in cognitive abilities will necessarily limit self-determination. Research findings do show a consistent relationship between self-determination and IQ scores (Stancliffe

et al., 2000; Wehmeyer, 1996; Wehmeyer & Garner, 2003). What is perhaps most striking about the relationship documented by this research is how relatively weak the correlation between IQ and self-determination is and the relative complexity of that relationship. Wehmeyer & Garner (2003) conducted a discriminant function analysis of predictors for self-determination scores for individuals with intellectual disability and found that only choice opportunity (from among four variables, including IQ score) predicted membership in a high self-determination group. Similarly, an 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 analysis 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 finding consistent with the previously reviewed literature on the relationship between choice and environment. Similarly, Stancliffe, et al. (2000) found that adaptive behaviour accounted for most of the variance in self-determination scores, and IQ contributed very little.

The gist of these findings is that while cognitive capacity may identify the level of support a person will need to become fully self-determined, the degree to

which that is achieved is as much a function of the environment, or the context, and the supports available to people to succeed in those environments as it is a function of intellectual or cognitive capacity. This speaks loudly to the need for a social-ecological approach that emphasizes personal capacity and the context in efforts to promote self-determination.

Religious Beliefs and Affiliation and Spirituality. Another moderator variable to mention involves religious beliefs and affiliations. In general, issues pertaining to religious beliefs and affiliation and spirituality can be subsumed under the context of culture, and most of what was discussed under that earlier section is relative to considerations of religious beliefs and affiliation. It is worth, though, being explicit about the importance of considering religious beliefs and affiliation because while they may co-occur or overlap with cultural context factors, that overlap is not complete. These beliefs appear to influence people's perceptions of health and disability, including the individual's role in attempting to control the situation or not (see Purnell & Paulanka, 2003 for examples from various cultures). Obviously, people of any given race or ethnicity differ in religious beliefs and affiliation, and it will be important to consider such beliefs and affiliations when designing and implementing interventions.

Experiences of Oppression, Segregation, and Discrimination. The final moderator variable includes a number of personal experiences that often inhibit the development of self-determination and personal realization. Oppressed individuals

are unable to see or recognize their capacity to transform their social reality and take charge of their own destiny. Most individuals with developmental disabilities are oppressed by exploitative labor conditions, controlling living arrangements, and/or lack of opportunities for independence among other factors. In addition, they experience countless instances of segregation and discrimination in education, employment, community living, and recreation that combine to inhibit their sense of worth. Unfortunately, these factors are common among the poor people of the world and worsen when combined with the experience of disability.

Conclusion

Self-determination refers to self- (vs. other-) caused action; to people acting volitionally, based upon their own will. Although the SD models presented here vary in some ways, they share common themes. First, all three, whether explicitly or implicitly, view self-determination within a developmental perspective. Becoming more self-determined is a critical milestone for adolescent development. Second, all three emphasize the role of personal capacity and the environment and context. They are person-environment fit models in which self-determination is an outcome of both the person's capacities and the environment in which that person functions. These common features are essential to considering the impact of moderating variables on the development of interventions to promote self-determination and lead to three assertions about promoting self-determination.

First, every culture in the world holds attitudes, values, goals, and practices

pertaining to the process that adolescents within that culture follow in moving from being a child to being an adult. These attitudes, values, goals, and practices vary widely, but the fact that they are universal implies that the psychological process of becoming self-determined, which might be seen as the ultimate outcome of individuation, is equally universal. As evidence of this fact of universality, the functional model of self-determination forwarded by Wehmeyer and his colleagues has been applied to groups that vary widely, from members of the Dine' (Navajo) nation (Frankland et al., 2004) to efforts to promote self-determination in South Korea (Bae & Wehmeyer, 2003; Lee & Wehmeyer, 2004), Japan (Ohtake & Wehmeyer, 2004), Italy (Nota, Ferrari, Soresi, & Wehmeyer, 2007), Belgium (Lachapelle et al., 2005), and China (Zhang et al., 2005).

Second, what is "self-determined" *behavior* in one cultural context may vary from other contexts, but as a construct, self-determination *itself* must be the same across cultures. Again, to be clear, what is viewed as manifestations of self-determination—that is, the action or behavior that functions to enable the person to act in a self-determined manner—will, necessarily, vary across people and contexts. Third, we believe that all moderating variables of relevance to interventions for promoting self-determination operate as a function of a person's interaction with his or her cultural context. The social-ecological model we have proposed herein systematically takes these person-context interactions into account in considering how to promote and enhance self-determination.

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