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## Invited Commentary

# Self-Determination by Individuals with Severe Disabilities: Limitations or Excuses?

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The five manuscripts in this special issue provide a helpful discussion of the status of the professional disability field with regard to understanding and advancing self-determination, and they remind me of the numerous barriers that keep individuals with severe disabilities from opportunities to determine and act upon their lives. As a professional with disability who has devoted much of my career to this topic, I am not particularly satisfied about what we have accomplished. However, despite my cynicism and as detailed by the authors, progress has been achieved in key areas. For example, several interrelated theories of self-determination have been articulated. We have documented the restricted opportunities that many individuals with disabilities, especially those with severe disabilities, have in expressing self-determination. Instructional approaches have been identified to assist individuals to learn skills associated with the expression of self-determination. And there is growing validation of the association between self-determination and achievement of life outcomes valued by Western society.

Mike Ward provides a comprehensive overview of the above achievements, many of which were spearheaded by key federal educational initiatives in self-determination over the past 15 years, as well as the key role of self-determination for increasing student success in general education. Ward and Wehmeyer highlight a recurring barrier facing students with severe disabilities; that is, too many professionals do not believe in their capacities for self-determination and fail to affirm or recognize their preferences. Ward shares his perspective that successful approaches include systematic instruction in self-determination and providing real choices and opportunities to practice skills, coupled with letting go of assumptions about what students can do. He reminds us that self-determination is owned by an individual; it is not a program, and strategies such as person-centered planning and brokering are just tools for enabling individuals to express self-determination. Ward highlights the dichotomy between self-determination and protection and challenges professionals, family members, and adult service systems to truly support persons with severe disabilities to have life options.

As reflected by the title of his paper, "Inching Toward Self-Determination . . . ," Jim Martin and his colleagues highlight the gradual progress that has been achieved in infusing self-determination opportunities within transition preparation, particularly for employment. He describes the evolution in transition preparation from placing students in any job to self-directed employment, as well as advancements in strategies for employment preference assessment. Martin also makes the familiar call for students with severe disabilities to have real opportunities for meaningful life choices. He challenges predominant approaches to career planning with individuals who have severe disabilities—observation and decision making by professionals and family members—by reporting findings from a small-scale study that documents widespread disagreement in vocational choice by individuals with severe disabilities and their "caregivers," and promotes the use of technology as a medium for directly assessing student preferences.

Dalun Zang discusses cultural perspectives on self-determination, reporting findings from another small-scale study comparing reports of self-determination–related behaviors and beliefs of parents of children with and without disabilities from different cultures and between first-generation immigrants and nonimmigrants. His findings are somewhat divergent from prior research and predominant cultural assumptions. For example, as might be expected, nonimmigrant parents and parents with higher levels of education and income reported that their children did more chores, dealt with salespeople, and made more important daily decisions than parents with less education reported for their children. Likewise, parents of students in special education generally reported allowing their children fewer oppor-

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tunities for participation in activities and daily decision making, and these parents expressed greater intent to control their children's future careers and living arrangements than did parents of children in general education. However, some of Zang's other findings were surprising. For example, Asian parents were significantly more likely than Caucasian parents to report that everyone in the family was equal, and they wanted their children to have a career that was best for the children. First-generation immigrants also expressed less desire than nonimmigrants to control their children's future career and living arrangements, desiring that their children have a career of their choice and live independently as early as possible. In discussing the findings, Zang highlights that the sample was unusually highly educated (50% of parents had college degrees), and he suggests that the results demonstrate that self-determination will be embraced by parents from non-Western cultures who are formally educated and acculturated to Western practices.

Wendy Wood, Catherine Fowler, Nicole Uphold, and David Test conducted a comprehensive review of studies designed to teach component skills of self-determination (i.e., self-determination components as dependent variables). Their review revealed that single subject designs were used most frequently, with the majority of studies investigating the effects of teaching choice-making skills. Other self-determination components taught to students with severe disabilities included self-instruction, self-monitoring, self-reinforcement, and problem solving. Of most interest was the finding that all studies suggested positive effects, suggesting that students with severe disabilities can be taught to use a variety of strategies associated with self-determination. One limitation of the paper was the authors' admission that approximately 20 studies were not included because the components served as independent variables rather than dependent variables. Nevertheless, the review provided a comprehensive analysis of self-determination components that have been investigated, as well as suggesting areas where future research is warranted (e.g., the effects of goal setting or self-advocacy).

Finally, Mike Wehmeyer, in reflecting upon his previous article in the 1998 special issue of *JASH*, discusses key barriers to self-determination faced by individuals with severe disabilities, including the low level of importance that teachers give to students expressing components of self-determination with the exception of choice making, ongoing skepticism that individuals with severe disabilities can be self-determining, and guardianship restrictions that reflect stereotyped low expectations for people with severe disabilities. Wehmeyer offers a detailed explanation of how his understanding and definition of self-determination has evolved since 1998, suggesting that definitional factors may have led to misunderstandings about the implications of being self-determining for individuals with severe disabilities, fueling beliefs that application of the construct in severe disabilities would result in supports being withdrawn from vulnerable individuals. Wehmeyer's revised definition relies less on the notion of personal control and focuses on self-determination as volition and intent. He seconds Ward's perspective that self-determination is not a program or limited to choice making, and reaffirms that although it may not be a legal right, self-determination has been embraced as a basic human right across the world (Degener & Koster-Dreese, 1995).

## So What's the Problem?

I began this commentary by expressing my disappointment with the progress achieved in understanding and advancing self-determination. Given all of the advancement noted in these papers, why am I disappointed? Although progress has been made in making the case for self-determination for the past 15 years, "making the case" is still where much of the focus remains today. As highlighted by these papers, significant energy continues to be directed toward justifying the relevance of the construct and/or responding to ongoing resistance to embracing self-determination for people with severe disabilities. Wehmeyer even graciously offers the possibility that misunderstandings about his definition of self-determination may have fueled resistance to the construct being accepted.

I do not believe that people are resistant because they have been led astray with misguided definitions. Fundamentally, our greatest barriers to advancing self-determination are stigma, fear, and lack of interest. Although most people aren't deliberately trying to "disenable" individuals from self-determination, a variety of supports, services, systems, and curriculum and planning approaches are in place to maintain traditional practices; roles have been established; and self-determination just isn't a priority. Self-determination is pushed aside when other priorities have greater weight (e.g., implementing educational standards, high-stakes testing), and most individuals with severe disabilities are not advocating for self-determination because they have not been exposed to the possibility that they could act on their lives, and they may have difficulty communicating their preferences. Many individuals with severe disabilities who are disenfranchised from their own potential for self-determination also are supported by individuals who are themselves disenfranchised due to poverty, lack of education, or disability, and they do not know how to advance self-determination for themselves or others.

Thus, although issues such as professionals' beliefs, definitional shifts, and differing perspectives of parents and children are real, I question whether all our efforts to "build the case" have actually distracted us from focusing on areas that could actually move the field

forward. In the past 10 years, how much more have we learned about the *nature and expression* of self-determination by individuals with severe disabilities? How much more *opportunity* have most students with severe disabilities had to make informed decisions and take action in their lives? How much more do we know about specific *approaches* to foster self-determination by individuals with severe disabilities? How much more have we learned about how *self-determination and support* can be complementary in enabling individuals to optimally determine, express, and act upon their desires? How much more do we know about the relationship between *self-determination, risk, and safety*? How much more do we know about successful approaches that could be used to shift the hearts and minds of self-determination skeptics?

Although the disability field generally endorses the inherent value of self-determination and individuals with disabilities are claiming self-determination as their human right just as it is for others, many professionals and family members continue to ask, "Is self-determination truly possible, important, or safe for people with severe disabilities?" Those of us working in the area focus a lot of energy on trying to convince others that the answer is "Yes," assuming that the question has a single, definitive answer and that this answer will somehow open up the gates of fear and resistance. If they really believed it, would they respond differently? We know from advancements in other areas such as deinstitutionalization and educational inclusion that justifying the merits of new approaches or even showing the benefits for individuals seldom leads to significant change. Rather, in most cases, widespread advocacy and/or legal action and repeated demonstration and systemic incorporation of approaches are usually the pathways to improvement. Growing emphasis on evidence-based practice makes gathering empirical evidence increasingly important as well.

## Advocacy and Policy Action

Led by people with disabilities and their family members and professional allies, advocacy efforts for advancing self-determination remain strong. However, additional focus is needed to ensure that advocacy efforts reach and involve school-aged students, particularly those with severe disabilities. Further attention also is needed on the social marketing of self-determination as not only a revered value, but also a vehicle for individuals to advance their quality of life and effectively use supports and services.

In the policy arena, the Individuals with Disabilities Education Improvement Act (IDEIA, 2004, § 602 34 (b)) and other disability legislation affirm the importance of self-determination (e.g., Developmental Disabilities Assistance and Bill of Rights Act, 2000, § 15,001 (a)(16); Rehabilitation Act, 1973, § 701 (a)(6)(A)). E.O. 12994, reauthorizing the President's Committee on Intellectual Disabilities, stresses the importance of autonomy and self-determination (with appropriate supports where needed) for people with intellectual disabilities and seeks to "promote . . . [their] independence, self-determination, and participation as productive members of society" (E.O. 12,994, Preamble, §6). Unfortunately, the gap remains in the application of these policy mandates in actual practice. For example, we recently analyzed 400 randomly selected IEP transition plans and found that only 40% of students with intellectual disabilities were present for their IEP meeting (Powers, Gil-Kashiwabara, Powers, & Geenen, 2005). Only 10.4% of students with intellectual disabilities had employment goal(s) listed on their transition plan; 8.5% of these students had a goal listed relating to postsecondary education. Ninety-two percent of students with an intellectual disability had performed a job or work experience that was rated as disability stereotypic compared with 42% to 55% of students with other disability classifications. Only 19% of goals listed on the plans included documentation of student desires or interests. Thus, although there is support in policy for self-determination, we have a long way to go in practice.

## Practice and Systemic Improvement

With legal and advocacy bridges built for advancing self-determination, the critical question becomes to what extent opportunities and supports for self-determination by students with severe disabilities have been identified, demonstrated, and infused within services and systems. Addressing this question gets at the heart of the challenge and highlights what I believe are really the most important barriers to advancing self-determination. Is the real problem that others don't believe it's possible for individuals with severe disabilities to be self-determining, or is it that they want to see evidence that it is possible and they want to know what are the implications in advancing self-determination for all involved—students, family members, educators, service providers, and administrators? Without clear answers to these questions, many people are not prepared to move forward in embracing self-determination, especially if this means they will be unsure of the outcomes or required to function differently, or services and systems will change in ways that are not familiar or desired. We must stop using disagreements in beliefs and concerns about feasibility and vulnerability as excuses for inaction, and instead we must directly undertake activities that address these critical issues. At the same time, we must partner with individuals with disabilities, self-advocacy groups, and other advocates to be sure the voice for self-determination remains strong, forcing skeptics to face these issues.

For example, Wolfensberger (2002) and others have expressed concern that promoting self-determination among individuals with severe disabilities will result in

supports being withdrawn and the lives of vulnerable individuals being further compromised. Self-determination researchers, including myself, have recurrently made the point that self-determination is an interdependent construct that requires individuals to both act themselves and to inform, guide, and manage the actions of supportive others (Powers et al., 1996; Powers, Sowers, & Singer, in press). Supportive others need to assist individuals to access information and experience life options so they have the opportunity to make informed decisions. Supporters must learn strategies that promote an individual's capacities to communicate and take action on his or her desires, and that increase the supporter's abilities to accurately discern what individuals are trying to act upon.

Thus, rather than treating "self-determination" and "support" as separate constructs, approaches must be identified that deliberately use support as a tool for self-determination enhancement, and use self-determination enhancement as a vehicle for individuals with severe disabilities to increasingly inform and direct those who support them. This perspective would shift the focus of Martin et al.'s work from documenting disagreement between caregivers and individuals with severe disabilities to identifying tools that enable people with disabilities to explore career options and ways that their family members, teachers, and others could share information and provide opportunities that assist individuals to discover their interests and resources. For those who are proponents of person-centered planning, this perspective would call for increasing focus on individuals to more independently explore their preferences and identify what they might need from their supporters. This information would be communicated to the individual's planning circle for feedback and support. The individual would, in turn, use the feedback received for further exploration of options. In some cases, support would be needed; in other cases, support would not be needed. Everyone would have responsibilities and be accountable, including the individual with a disability. We need to identify, validate, and apply methods for carrying out these activities; for requiring accountability; and for allowing the dignity of risk while also not turning our backs on an individual's support needs.

At the systems level, many important concerns and issues must be acknowledged and addressed if self-determination is to be a reality for individuals for severe disabilities. For example, the range of career options available to individuals with disabilities must be expanded. As Martin et al. suggest, technology has great promise as a tool for introducing individuals to career options. However, much of the benefit is lost if the options presented are limited to disability stereotypic areas such as food service, maintenance, landscaping, and stocking, to name a few. Why can't individuals have the opportunity to experience the diversity of jobs performed in health care, law offices, trades, and universities? How can technology be used as a tool for facilitating individuals with severe disabilities to perform various job duties?

If individuals are going to be self-determining, options and supports have to expand, and systems and support providers must stop doing some activities and begin doing others. Unfortunately, many schools remain locked into placing students in segregated, disability stereotypic work experiences that prepare them for sheltered workshops. Coffee carts and school maintenance crews must give way to community job shadows, internships, and access to general vocational education opportunities. Rather than "preparing" students for a self-determined life, schools must be providing information, experiences, support, and resources for students to discover, strengthen, and express self-determination throughout their school experience. For example, promising approaches from adult self-determination models (e.g., Moseley, 2001; Phillips et al., 2003) could be translated to school settings, providing opportunities for students to select, train, and supervise their aides and redesign transition programs to convert fixed services into flexible dollars and supports that students and their trusted others could access to pursue the student's transition goals. These reforms would constitute major systems change for most school districts, requiring models to draw upon business planning technical assistance and partnerships with families and individuals with disabilities to accomplish such restructuring. This is the reality of where self-determination leads, and it's time to move forward with vision, commitment, and well-designed strategy.

Addressing these system issues also relates to the point made by the authors that self-determination neither is limited to choice making nor is a program, highlighting approaches that have become popular in adult self-determination initiatives, such as person-centered planning and brokerage, where choice is emphasized and references are sometimes made to "doing self-determination" as if it's something owned by the system rather than the individual. This caution is important and must be applied to the school setting as well so that exposing students to self-determination curricula does not become the defining characteristic of "doing self-determination." In all cases, such approaches are tools that individuals should have the opportunity to access in flexible ways to facilitate their decision making *and* self-directed action.

As Zhang suggests, advancing self-determination will also require directly addressing questions about cultural applicability. Although Zhang's pro-Western acculturation perspective is one approach to advancing self-determination, I question the wisdom of advocating for the adoption of Western practices by citizens from other cultures, something that Westerners have done throughout history, stimulating fear and anger.

Much of the discourse on cultural meanings of self-determination has involved a debate about whether self-determination exists in other cultures and whether we as Westerners should push our self-determination perspectives on others who may not share our beliefs. Although interesting, I think that much of this discussion reflects misunderstanding of the construct of self-determination and misses the point. Many have confused the concept of self-determination with independence and separation from family, thus associating self-determination with achievement of particular favorite middle-class Western outcomes. However, as Wehmeyer points out, self-determination is characterized by volition and intent, not the achievement of particular goals or the application of particular practices.

From this perspective, we should be investigating cultural perspectives and practices relating to how individuals decide what's important in their lives and express their desires through action. A self-determining person from a culture that emphasizes collective or family priorities may decide that following family tradition is most important and may express a high level of self-determination in living a family-focused life. Likewise, although those from Western culture may favor future planning as a method to stimulate self-determined thinking, individuals from another culture may favor talk with an elder, prayer, or a variety of other approaches. The approach doesn't really matter. What matters is the extent to which people have the opportunity to decide and take action on what's personally important to them. Self-determination is owned by the person and expressed within the social and cultural context in which he or she lives. Applying this perspective of self-determination, Western acculturation could be a source of great confusion, sending the message that an individual isn't expressing self-determination unless he or she makes certain types of decisions that reflect Western traditions, even though that individual may have a long history of decision making and action consistent with his or her values and preferences. There is so much that we need to understand more clearly about how people from diverse cultures decide what is important in their lives and to take action to realize their desires. Just as in Western culture, we need to learn more about the role of family and society in influencing self-determination within other cultures, operating from the assumption that such influence can be promoting as well as inhibiting.

## Evidence-Based Practice in Self-Determination

My final comment is a reflection on the pressing need for additional theory-driven, empirical research to be conducted in self-determination, meeting current standards for evidence-based practice (National Research Council, 2002). Consistent with being a new area of investigation, much of the self-determination research conducted to date has entailed surveys using purposeful sampling, qualitative studies, and intervention studies without experimental control. If we are to move forward the knowledge base and credibility of self-determination research, additional research must be proposed, funded, and undertaken, using representative sampling and experimental or quasi-experimental designs. There are certainly many issues and approaches to investigate and evaluate, particularly for people with severe disabilities. Answers to many of our questions can best be obtained through participatory action studies conducted by researchers, individuals with disabilities and their family members, and education and service professionals.

In writing this commentary, I dream of a future in which we cease to ask the question, "Can people with severe disabilities be self-determining?" In this future, the question is no longer relevant because, as a result of focusing our hearts and minds on enabling individuals to be as self-determining as possible, there is no longer a need for an answer.

## References

Degener, T., & Koster-Dreese, Y. (Eds.). (1995). *Human rights and disabled persons: Essay and relevant human rights instruments*. Netherlands: Kluwer Academic Publishers.

Moseley, C. (2001). *Self-determination for persons with developmental disability: Final and summative program report*. Durham, NH: Institute on Disability, University of New Hampshire.

National Research Council. (2002). *Scientific research in education*. Washington, DC: National Academies Press.

Phillips, B., Mahoney, K., Simon-Rusinowitz, L., et al. (June 2003). *Lessons from the implementation of cash and counseling in Arkansas, Florida and New Jersey: Final report*. Princeton, NJ: Mathematica Policy Research, Inc.

Powers, K., Gil-Kashiwabara, E., Powers, L. E., & Geenen, S. (2005). Transition planning: Addressing IDEA mandates and effective practices. *Career Development for Exceptional Individuals, 28*(1), 47–59.

Powers, L. E., Sowers, J. S., & Singer, G. H. S. Person-directed long-term services. *Journal of Disability Policy Studies,* in press.

Powers, L. E., Wilson, R., Matuszewski, J., et al. (1996). Facilitating adolescent self-determination: What does it take? In D. J. Sands & M. L. Wehmeyer (Eds.), *Self-determination across the life span: Independence and choice for people with disabilities* (pp. 257–284). Baltimore, MD: Paul H. Brookes.

Wolfensberger, W. (2002). Social role valorization and, or versus, "Empowerment." *Mental Retardation, 40,* 252–258.

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