

An Historical Perspective of Self-Determination in Special Education: Accomplishments and Challenges

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Self-determination for people with severe disabilities first appears in the 1972 writing of Benget Nirje, where he came to the realization that they could and should have a role in their own choices (Shapiro, 1993). Nirje's writings called for a wide range of actions that would enable them to better control their lives and destinies, including choice and control over personal activities, education, independence, participation in decisions, and information upon which to make decisions and solve problems (Agran & Wehmeyer, 2003). Nirje equated self-determination with the respect and dignity to which all people are entitled. He identified making choices, asserting oneself, self-management, self-knowledge, decision making, self-advocacy, self-efficacy, self-regulation, autonomy, and independence (although often not using those terms) as the salient features of personal self-determination (Agran & Wehmeyer, 2003; Nirje, 1972).

Robert Perske (1972), a contemporary of Nirje and an advocate for the rights of people with severe disabilities, called for the opportunity for them to experience the "dignity of risk":

The world in which we live is not always safe, secure and predictable ... Every day that we wake up and live in the hours of that day, there is a possibility of being thrown up against a situation where we may have to risk everything, even our lives. This is the way the real world is. We must work to develop every human resource within us in order to prepare for these days. To deny any person their fair share of risk experiences is to further cripple them for healthy living (p. 199).

Nirje and Perske's calls for action to support self-determination and the opportunity to experience the dignity of risk laid the foundation for the special education initiative and presented challenges in actualizing their call for adults with severe disabilities. These challenges will be addressed later in this paper.

The OSERS Self-Determination Initiative

I feel honored to be considered a catalyst in introducing the concept of self-determination to the field of

special education. Looking back to 1988, several elements almost randomly aligned to create what I now believe to be a magical moment or a spontaneous combustion resulting in the Office of Special Education and Rehabilitative Services (OSERS) self-determination initiative. This initiative received support and encouragement from several leaders in the disability field, first and foremost being Madeline Will, Assistant Secretary for OSERS, and Patricia McGill Smith, Deputy Assistant. Ms. McGill Smith formed a work group of OSERS employees with disabilities and asked us to develop an initiative to (a) focus on system-wide activities, (b) promote service systems to include consumers in decision making, and (c) increase the pool of future leaders with disabilities (Ward & Kohler, 1996).

A key milestone of this initiative occurred in January 1989 when 60 people, more than half of whom were people with disabilities, gathered at the National Conference on Self-Determination. Colleen Wieck from the Minnesota Governor's Council on Developmental Disabilities organized the conference and Robert Perske edited the conference report containing 29 recommendations for promoting self-determination across Federal agencies (Wehmeyer, 2004).

As Chief of the Secondary Education and Transitional Services for Youth With Disabilities Program, I focused on the importance of Recommendation 20 ("a series of model programs be funded that exemplify self-determination attitudes and practices") and interpreted it to be my marching orders. OSEP announced a grant competition in September 1989 for model demonstration projects to "identify and teach skills necessary for self-determination, as well as the in-school and out of school experiences that lead to the development of self-determination."

Twenty-six model demonstration projects were funded through this competitive priority over a 4-year period (Ward & Kohler, 1996; Wehmeyer, 2004) and included many innovative approaches (Ward & Kohler, 1996) that focused on youths with severe disabilities. Several projects used a futures planning or person-centered planning process to teach strategies for achieving self-determined futures. Another project

taught us the importance of having dreams in the self-determination process by supporting youths with severe disabilities to use a picture card deck to identify and actualize their dreams. Two projects adapted the self-advocacy strategies of "People First" for the adolescent population. These are examples of model projects that convinced the field, myself included, that youths with severe disabilities could benefit from instruction in self-determination skills.

Paula Kohler, Professor at Western Michigan University, and I analyzed the applications of the 26 projects to identify specific practices and approaches related to teaching and applying self-determination (Ward & Kohler, 1996). This analysis indicated that most of their curricula focused on skills related to self-advocacy, decision making and goal setting, use of community resources, creativity and self-expression, assertiveness and self-actualization, and empowerment and social independence.

The Body of Knowledge on Self-Determination in Special Education for Students with Severe Disabilities

Prior to the OSERS initiative, special education researchers were working toward helping students with severe disabilities control their lives. Mithaug, Martin, and Agran (1987) developed the *Adaptability Instructional Model* to teach students with disabilities how to regulate their own behavior by (a) teaching students to identify and set goals, (b) engaging in independent performance through self-monitoring, (c) evaluating their performance in terms of an existing standard, and (d) learning from their mistakes and adjusting their goals. This model was later used to teach learning strategies that allowed students to modify and regulate their own behavior (Agran, 1997) so that they can become active participants in their own learning and to enhance self-determination. Students learned strategies as how to set their own learning goals, monitor their own performance, identify problems and identify solutions to present or future problems, verbally direct their behavior, administer reinforcement, or evaluate their own performance, respectively (Agran & Wehmeyer, 2003). Self-regulation strategies have been demonstrated across a wide age range of learning and adaptive skills and have been well validated and supported in the literature (Agran, 1997; Agran & Wehmeyer, 1999; King-Sears & Carpenter, 1997; Wehmeyer, Agran, & Hughes, 1998).

There is a growing body of research literature suggesting that student-directed learning strategies enhance a student's participation and success in general education. For instance, Gilberts, Agran, Hughes, and Wehmeyer (2001) taught five middle school students with severe disabilities to self-monitor a set of survival skills in their general education classrooms. Likewise, Copeland, Hughes, Wehmeyer, Agran, and Fowler

(2002) taught four high school students with mental retardation self-regulation strategies to increase their level of performance of specified study skills in general education cosmetology classes and increased all of the students' grades to satisfactory levels. Finally, Agran, Blanchard, Wehmeyer, and Hughes, (2001) taught six secondary-level students with varying disabilities to use student-directed learning strategies to modify selected academic, study, and social skills. All students increased their performance levels from 0% to 20% to 100%. It is important to note that without an opportunity to practice and improve their self-determination skills, these students would not have had any access to the general education setting.

Wehmeyer (1998) stresses that the construct of self-determination often includes having control in one's life. However, this opens the question concerning the degree to which students with more severe disabilities can really control their lives by making complex decisions or solving complex problems. Sadly, far too many teachers who work with students with severe disabilities believe that the skills and knowledge related to enhanced self-determination (e.g., problem solving, decision making, goal setting) are too complex for their students to learn (Agran & Wehmeyer, 2003).

Agran and Wehmeyer (2003) suggest that there are multiple barriers to choice making for individuals with more severe disabilities. Many individuals with severe disabilities have too few opportunities for choice and therefore do not know how to make choices and need targeted, systematic instruction to do so. Other individuals with severe disabilities do not express their preferences in a discernable and consistent manner, resulting in even more limited opportunities to express their choices (Brown, Belz, Corsi, & Wenig, 1993; Dattilo & Rusch, 1985). It is not they do not have preferences, but rather professionals, family members, and others are not always able or willing to recognize and affirm their expression of preferences (Dattilo & Miranda, 1987) and to make the efforts to eliminate these barriers. For example, it is easier to assume that Johnny wants chocolate chip ice cream because he seems to like this flavor, rather than taking the time to set up his communication device and wait for him to slowly type his preference.

A Personal Perspective of Self-Determination

Based on my role with the OSERS initiative, I have learned several lessons. The first is that self-determination is important and is best learned through participation in a specific curriculum. An emerging literature base shows that self-determination does have a positive impact on postsecondary and quality-of-life outcomes, including helping students learn to make decisions, be assertive, and self-advocate (Ward &

Kohler, 1996; Wehmeyer, 2004). Wehmeyer and his colleagues performed two follow-along studies (Wehmeyer & Palmer, 2003; Wehmeyer & Schwartz, 1997) and found that students who left school as self-determined young people had more positive adult outcomes than their peers who were not self-determined in a number of areas, even though these groups were equivalent in their personal capacities and learning opportunities. Self-determined students were more likely to live outside their family home, experience greater independence, and work at jobs offering better pay and benefits.

The second lesson is that it is imperative that youths with disabilities receive training in school to develop self-determination skills, have multiple opportunities to practice these skills, and receive skill reinforcement from their parents as well as additional opportunities to practice (Ward & Kohler, 1996). Too many parents have difficulty perceiving their child as becoming an empowered and self-determined adult. One benefit of the increase in postsecondary opportunities for people with severe disabilities is that many of these programs focus on meaningful functional skills, including self-determination activities (Grigal, Neubert, & Moon, 2001).

Another lesson is not to deny or limit a person's right to self-determination based on a label or classification. Individuals with severe disabilities can learn to self-regulate and self-manage their own behavior and express preferences and use those preferences to make choices (Wehmeyer et al., 1998). The person-centered future planning procedures implemented in the past decade have shown that people with severe disabilities can be involved in the decision-making process, including making decisions about their own lives (Mount, 1994; Turnbull et al., 1996). The self-advocacy movement has shown that people with severe disabilities can assertively advocate for their own rights and needs, and the rights and needs of all people with disabilities (Dybwad & Bersani, 1996). Thus, people with severe disabilities can be involved in self-determination on both a personal level and a collective level by enabling them to maximally participate in their lives and communities when the necessary supports and accommodations are in place (Wehmeyer, 1998).

Challenges

The fields of both special education and adult services have made great strides in supporting self-determination for persons with severe disabilities, but critical challenges remain. Wehmeyer, Agran, and Hughes (1998) conducted a national survey of teachers of secondary students with mental retardation regarding their perceptions about the value of self-determination. Sixty percent indicated they were familiar with the term "self-determination," and the majority

of teachers believed that promoting self-determination would be "very helpful" in preparing their students for success in postschool life and "somewhat helpful" in ensuring their success in school. However, teachers working with students with more severe disabilities were significantly less likely to rate self-determination strategies as important for their students to learn, and consequently were less likely to provide instruction to their students on how to use these strategies. Service professionals must be trained in methods of supporting self-determination along with the philosophy of why this is imperative.

Agran and Wehmeyer (2003) point out that self-determination is not a program or the way someone does something. Person-centered planning, individual control of service dollars, and brokering efforts have been referred to as "doing self-determination" in adult services. Such efforts fail to recognize that self-determination is not about a way to do planning or provide services, but instead about enabling people to make things happen in their lives. Although these valuable efforts are well intended, they are just tools to help persons with disabilities become self-determined. Self-determination, first, foremost, and always, is about the SELF. It is about taking control over one's life to the extent possible or desired by the individual.

Self-determination is not reflected in solely having choice; it is about the process of choosing or decision making based on having an array of desirable options. Choice is important and requires a minimum of three options:

- (A) A desirable option (going to a movie)
- (B) Something other than "not A" (not going to a movie and staying in the group home)
- (C) A rejection of A and B in search of C (otherwise known as "none of the above; let's find other options")

Self-determination is an abstract concept and not about obtaining specific outcomes, although outcomes such as owning a home, having a good job, and self-advocating are of course important and desirable. Self-determination is about empowering people with severe disabilities by providing skill instruction and opportunities to practice choice and decision making so that they themselves can obtain the outcomes they desire.

Future Directions: A Systems Shift

With the continued call that students with disabilities have access to the general curriculum, it is unclear how self-determination will fit into its context. Elements of self-determined behavior, such as goal setting and attainment skills, problem-solving skills, self-advocacy skills, and self-management and self-regulation skills, are found throughout general education standards in that all students need instruction in these areas (Weh-

meyer, 2004). Yet without specific instruction in self-determination skills and teachers' recognition of the value of these skills, self-determination may fall by the wayside.

Although this special issue of *RPSD* focuses on self-determination in special education, it is important for parents of children and youths with severe disabilities and the professionals working with them to understand how self-determination extends to adult service systems and to advocate for the principles we hold dear. We must keep pressing these systems to change the way they think about and serve people with severe disabilities. We must prevent these systems from seeing persons with disabilities as having limitations that exclude them from participating fully in life rather than as valuable citizens who have many talents, strengths, and abilities to contribute to their communities. We must prevent these systems from seeing persons with disabilities as service recipients rather than as individuals with rights and entitlements.

Conclusions

In my initial writing on self-determination, I cautioned that many young persons with disabilities have difficulty with the processes of autonomy and individualization, critical for self-determination (Ward, 1988). It is difficult to be independent psychologically and emotionally when they depend on their parents and other care providers to attend to their physical needs. Even when persons with disabilities become independent of their parents, they still often face overprotectiveness and over-structured environments imposed by those around them (Wehmeyer, 1992). Based on my experience in the field of developmental disabilities, this caution continues to hold true.

There is a polarizing dichotomy in the field of severe disabilities, especially developmental disabilities. There are many who subscribe to the goals of self-determination and believe in concepts and outcomes such as autonomy, choice, empowerment, real jobs, and meaningful participation for people with severe and developmental disabilities. They are, I believe, overshadowed by a large proportion of this field who continue to feel that this population needs maintenance and caretaking in safe, secure environments. They do not understand self-determination and self-advocacy and are critical of those who advocate for it. They deny people with severe disabilities the "dignity of risk."

Many self-advocates I have met are painfully aware of these attitudes. Self-Advocates Becoming Empowered (SABE), a national coalition of self-advocates and self-advocacy groups, initially decided not to attend a recent national summit on the full participation of people with disabilities. SABE felt they were being given only token involvement in the planning and administration of the summit by the developmental dis-

abilities organizations that were sponsoring it. Chester Finn, its Chair, justified this decision based on SABE's philosophy to support:

self-advocates across the nation to speak up in order to gain their independence. Our mission is to ensure that people with disabilities (a) are treated as equals, (b) are given the same decisions, choices, rights, responsibilities, and chances to speak up to empower themselves, and (c) are given opportunities to learn from mistakes, as everyone else. (C. Finn, personal communication, Feb. 14, 2005)

Mr. Finn's letter also included specific issues for the summit planners to address to achieve the goals of "closing institutions and nursing homes, self-determination, individualized services, self-directed supports, and money following the person. All of these goals are related to making real lives for persons with disabilities." Although SABE eventually negotiated an agreement on their participation in the summit, I wonder to what extent their cries for self-determination will be acknowledged and receive a deserved response.

Self-determination is an interplay between the individual and society. Individuals with disabilities must have the abilities and opportunities to be self-determined. Society must give individuals with disabilities, including those with severe and developmental disabilities, the skills, opportunities, and the support to do so. My challenge to TASH and others working with individuals with severe disabilities is to address the dichotomy of self-advocacy and well-meaning but often overprotective parents and professionals. TASH must ensure that true self-determination is promoted and endorsed on both levels.

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