

Self-Determination: An Overview

by Julie Maier
CDBS Educational Specialist

A toddler chooses his favorite flavor out of the Popsicle box. A first grader gets mad when another student takes his ball on the playground and then decides to go ask him to return it. A fifth grade girl writes out a plan for completing an upcoming history project including trips to the library for research and an art store for supplies. A high school freshman explains to his parents and counselor his core academic and elective class choices for the following year. A high school junior meets with her counselor and a favorite instructor to identify internship opportunities for the upcoming summer.

What does each of these examples have in common? In each scenario, the individual is demonstrating self-determination skills. Making choices or simple decisions, solving problems or conflicts, and setting daily plans or more long-term goals are all evidence of this important developmental characteristic. Self-determination is a highly valued and important factor in the development of youth in our society, yet the opportunities to develop this skill are often not made available for students with combined sensory and intellectual disabilities. Why is that the case? Why aren't these skills encouraged, taught and reinforced? Who determines if these skills are meaningful and relevant in an individual's life? Are we presuming these skills cannot be learned or are not necessary because these individuals have other people supporting them who can more easily and "expertly" make the choices and decisions, solve the problems, and determine individual goals and progress toward meeting them?

Self-determination is generally defined as "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). Self-determination is highly valued by each of us and serves as an important marker of an individual's sense of quality of life. It is valued both on a personal level and in terms of how others view a person's competence. Certainly individuals with well-developed skills in this area tend to have a stronger and more positive self-image. They understand that they have control over important decisions in their lives and that they are responsible for the goals they set and achieve. For the most part we view individuals who can make wise, healthy, ethical choices and decisions, identify and solve problems, and set goals and monitor their progress toward meeting them through self-regulation and self-assessment as competent, secure, and productive members of our classrooms, workplaces and schools.

Self-determination is comprised of eight key components that include a class of behaviors and skills that continually become more sophisticated and complex. The components are in order from basic to more complex:

- Choice-making
- Decision-making
- Problem-solving
- Goal-setting and attainment skills
- Independent living skills (risk-taking and safety skills)
- Self-observation, evaluation, and reinforcement skills
- Self-instruction skills
- Self-advocacy and leadership skills

It is easy to see from this list how acquiring the earlier competencies can lead to more success in developing the more advanced skills. The ultimate goal is an individual who can successfully advocate for their own desires, concerns, goals and support needs.

Self-advocacy requires an accurate assessment of one's skills, strengths and personal goals and the necessary supports to achieve those goals. When advocating for oneself an individual is required make choices and decisions concerning available opportunities, options and scenarios; at times use problem-solving and self-evaluation skills to make those informed choices and decisions. Acquisition of skills in self-assessment and self-advocacy will allow individuals to exert control over their life decisions without undue influences from others. It is important to remember that self-determination does not mean that one has absolute control at all times. However the individual remains the causal agent in his or her life as the individual actively chooses to grant control to another who may be more able or qualified to act on their behalf.

Historically, the development of self-determination has not always been expected of or offered to individuals with disabilities. In the early 20th century individuals with disabilities, especially those with combined intellectual and sensory disabilities, were viewed as a menace or as people to be feared and avoided. By the mid-20th century perceptions shifted as society became more aware of individuals with physical disabilities due to World War II. However individuals with intellectual disabilities were still not viewed as capable and contributing members of society, but rather as "eternal children" who did not have the capability to demonstrate self-determination and required others to care for them.

Stereotypes of such individuals began to change a great deal in the 1960s with the emergence of the disability rights movement and advocacy movement, which then expanded to the field of special education and support service providers and eventually to the greater society. Four key contributing factors to this shift in perceptions and expectations of individuals with disabilities were: 1) introduction of the normalization principle, which stresses the importance that individuals with intellectual disabilities be engaged in the normal activities of everyday life within their home communities and be offered the same respect that others in the community are given; 2) the rise of independent living and self-advocacy movements; 3) the shift from institutions to community-based services; and 4) civil rights legislation and protections such as

Section 504 of the Rehabilitation Act (1973), the Education of All Handicapped Children Act of 1975 (which later became the Individuals with Disabilities Education Act or IDEA), and the ADA (Americans with Disabilities Act, 1990). (Wehmeyer, Agran, Hughes, 1998).

This is important for educators and families who support children and youth with more significant needs to keep in mind because this group continues to be limited in opportunities and instruction in self-determination. There are a number of possible reasons that this is occurring: ongoing societal misperceptions about the capacities of and expectations for individuals with more significant disabilities; a lack of understanding of what self-determination entails and how it can be meaningfully adapted for these students; educators and families have limited knowledge of available curricula or activities to teach and practice self-determination skills; concerns about risks and safety when supported students are allowed to make their own decisions or set personal goals; and finally, a belief that self-determination is simply not important to students with more significant intellectual and sensory impairments. This last reason is the most troubling of all as it is based on the assumption that choice, autonomy, and strong self-identity are not understood and/or valued by these students.

When I visit classrooms, I often see the support providers providing students with numerous choices across activities, and this is a good practice. However, self-determination is more than simply making choices. It is about being offered meaningful options that impact a student's life in both small ways (what to eat, what to wear, what game to play) and large ones (high school course selection, vocational interests and training, living arrangements). Additionally, each student needs a way to effectively communicate his or her preference when offered the opportunity, as well as how to ask for choices in situations where they feel they have no control. A student needs to recognize that by making a choice they are asserting themselves and letting others know what they want, think, and feel and that the other people in their life are listening, respecting and responding to them. Lyle and Mary Romer highlighted the importance of meaningful choice opportunities in this way:

“Self-determination means making choices; it also means standing up for those choices in ways that others describe as noncompliant, stubborn, non-cooperative, and so on. It is a crucial accomplishment in all matters of quality of lifestyle. Without some degree of self-determination, all other aspects of one's lifestyle diminish in value. Self-determination is a complex issue for all of us, and especially so for people who have limited means of making themselves understood by others and for people who have had limited opportunities to participate in the diverse range of activities and events available to other students and community members... Making choices is a significant way of defining one's own individuality. When others make choices for us, we are seen as less capable and, therefore, less of a person in our own right.” (Romer & Romer, 1995).

For the past four decades people with disabilities and their allies have demonstrated these individuals' capacity for self-determination, the accomplishments they can achieve, and the value of their contributions to society. As educators and family members concerned about positive quality of life outcomes for students with deaf-blindness we need to continue to

promote a similar capacity-building perspective for our students and children. We need to hold expectations that these children and youth can and will make meaningful choices and decisions; participate, even in a partial way, in problem-solving and goal setting and attainment; contribute to and evaluate their progress and goals; and learn to advocate for themselves. Of course, this will look different for each student as the skills taught and practiced must be matched to the student's skills, interests and motivations, and support needs. Yet, by starting from a capacity-building rather than deficit-framing perspective, we at least will be able to begin to identify meaningful activities, routines, and times for instruction and support of self-determination skill development.

Recently David Brown and I observed a 4th grade age student with deaf-blindness in his school program. This child was primarily a visual learner with emerging skills in sign language use, which he used both expressively and receptively. He had a positive, strong, and respectful relationship with his intervener and it appeared that most of the classroom staff could identify his strengths, abilities, and motivators. During our visit we were thrilled to see this student demonstrate many important developing skills in self-determination. He was clearly able to make informed choices through the information provided to him through visual signs, a communication choice book, and a variety of materials presented to him to explore.

It was also exciting to see that he also articulated his likes and dislikes. At lunch he made it very clear that all the beans had to be separated from the meat in his burrito. Midway through his meal he led a support staff person to the cupboard and requested through gestures and signs the chips he had brought to school for snack. When he returned to the table and the chips he had been given were later taken away until he finished his burrito, he very clearly and firmly made a strong request to have the chips returned through signs, vocalizations, and stamping his feet. The classroom teacher acknowledged his actions as communication of a protest rather than "problem" or "noncompliant" behavior and asked the staff to return the chips to him. The outcome was that this student learned that his desires were understood and acknowledged and he was able to regain control of the situation. This was a very reinforcing experience for him and can be seen as a context in which to promote more acceptable means to make firm and strident requests or protests.

We saw similar situations across the day, more often when he was enjoying activities such as a guided cane walk around campus with his intervener or exploring wind-up toys during a session with a teacher of the deaf/hard-of-hearing. During these times his requests for continuation of the activity or changes in the flow or pattern of it were immediately recognized, acknowledged, and responded to by the staff working with him. Perhaps without knowing it, the staff was effectively employing "follow the child" techniques, which were not only promoting positive reciprocal relationships and the development of clear communication, but also teaching and supporting this boy to demonstrate meaningful self-determination skills. (For further discussion of the importance of the development of self-determination for individuals who are deaf-blind I suggest reading David Brown's article "Self-determination is for Babies, Too!" in the Spring 2011 reSources. Here David offers his views about promoting self-determination across a child's life and provides specific practices and strategies to employ to build a child's repertoire of self-determining skills.)

Now think back to the scenarios presented at the beginning of this article. What are the meaningful opportunities across the day at school and at home where we can support children and youth with deaf-blindness to make informed choices, participate in decision-making, solve problems, set goals, monitor progress toward achieving them, and advocate for themselves (even in simple ways such as gaining access to prized potato chips!)? The opportunities offered have a lot to do with our expectations for these individuals and our understanding that self-determination is essential to a valued quality of life for everyone.

References

Brown, D. (2011). Self-determination is for babies, too! *reSources*, 16(2), 1-6. Retrieved from <http://www.cadbs.org/newsletter/resources-spring-2011/>.

Romer, M. & Romer, L. (1995). Developing educational plans to support values lifestyles. In N. Haring and L. Romer (Eds.), *Welcoming students who are deaf-blind into typical classrooms*, p. 110. Baltimore: Paul H. Brookes Publishing Co.

Wehmeyer, M. L. (2005). Self-determination and individuals with severe disabilities: Reexamining meanings and misinterpretations. *Research and Practice for Persons With Severe Disabilities*, 30(3), 113-120.

Wehmeyer, M., Agran, M., Hughes, C. (1998). *Teaching self-determination to students with disabilities*. Baltimore: Paul H. Brookes Publishing Co.