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ABSTRACT

This theme issue explores the relevance of self-determination for persons with developmental disabilities across the life span, ways in which it is or can be expressed, and obstacles to its exercise. The articles show the futility of enhancing self-determination by teaching choice-making skills if environments offer no opportunities to exercise them; offer strategies for facilitating self-determination; and present examples of individuals with developmental disabilities claiming their right to direct their own lives. Titles and authors of major articles include: "Standing Together: One Family's Lessons in Self-Determination" (Kris Schoeller); "Self-Determination: It's Not Just for Adults" (Brian Abery); "Facilitating Self-Determination through Early Intervention" (Ann Eggebeen and Annetta Leigh); "Daily Self-Determination for Young Children" (Jean Mendenhall and Marijo McBride); "Self-Determination as an Educational Outcome" (Michael Wehmeyer); "Self-Determination: A Means to an End" (Michael J. Ward); "MAPS: A Strategy for Promoting Self-Determination" (MaryBeth Doyle and others); "Transition and Self-Determination: Putting the Promise into Practice" (Sandy Thompson and Stephanie Corbey); "People First Facilitates Student Self-Determination" (Ruthie Beckwith); "A New Era of Self-Determination" (Michael D. West and others); "Guardianship and Self-Determination" (David Flower); "The Journey toward Self-Determination" (Peter "Skip" Sajevic); and "What about Environment?" (Brian Abery and John Smith). (JDD)

IMPACT

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Feature Issue on Self-Determination

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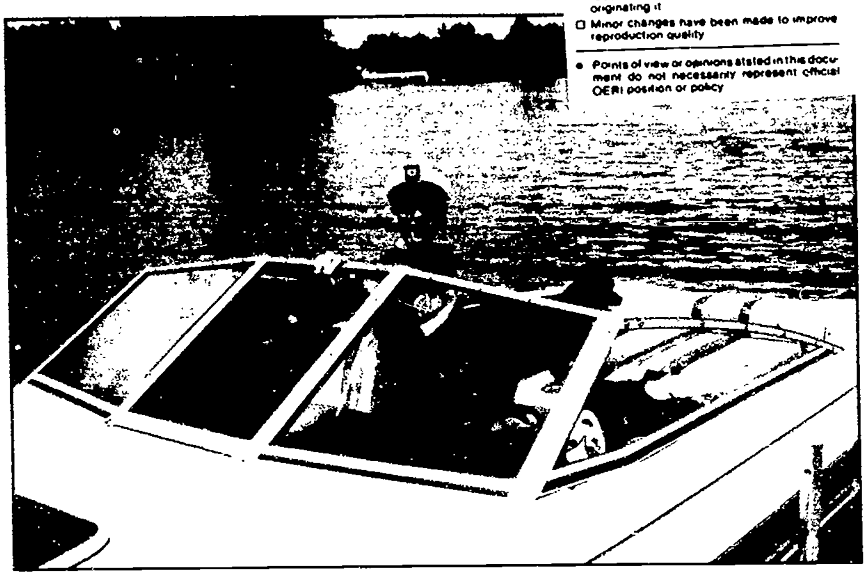

In piloting his boat as well as his life, Christian Schoeller is learning to set a course, navigate through obstacles and changing conditions, and recruit a crew to assist him. See story below.

Standing Together: One Family's Lessons in Self-Determination

by Kris Schoeller

Self-determination is not synonymous with independence. Rather, it is best facilitated by interdependence: connections and support from those around us. Our brain, our spirit, our emotions, our psyche, and our sexuality all function better in social interaction than in isolation. For my son, Christian, it has been this positive interaction that has allowed him to experience more choices and opportunities, leading to his determined spirit. These are some examples that he would like shared with everyone:

> Christian stood up and lowered his eyes. He spoke clearly and was firm. "I will not take Speech and Language anymore. It's always the same thing and it's for babies. I will take a language class but no more therapy!"
>
> It was the second week on a new job and Christian noticed that all the employees went to a meeting, but that he was not included. He said nothing, but brought home his anger. The next day he went to his supervisor and said, "I work here too. Why can't I go to the meetings?"
>
> He woke at 5:30 every morning and caught the bus for school at 6:15, arriving home at 4:30. Of those 10 hours, half were spent on the bus. In addition to the frustrations of this demanding schedule, he had a

Family, continued on page 19

From the Editors

Self-determination. A complex term for a seemingly simple concept: persons controlling their own lives. Yet this simple concept is often misunderstood, ignored or seen as applicable only to persons without disabilities.

This issue of IMPACT explores the relevance of self-determination for persons with developmental disabilities across the life span, ways in which it is or can be expressed, and obstacles to its exercise. Those who authored the articles in these pages take many different views of this simple concept. Some show us that we often attempt to enhance self-determination by teaching choice-making skills while forgetting that those skills are useless in environments that offer no opportunities to exercise them. Others place the issue of self-determination within a life-span perspective in which opportunities to learn and attempts to control one's environment occur at all ages and in all settings. Some offer strategies for facilitating self-determination. And, most powerfully, individuals with developmental disabilities and their families talk about claiming their right to direct their own lives.

It is our hope that this IMPACT will raise awareness about the need and capacity for self-determination by persons with developmental disabilities, and of ways in which others either support or hinder it.

CONTENTS

A publication of the Institute on Community Integration (UAP) and the Research and Training Center on Residential Services and Community Living, College of Education, University of Minnesota. Dedicated to improving community services and social supports for persons with disabilities and their families.

Self-Determination: It's Not Just for Adults

by Brian Abery

The belief that human beings have an inherent need to exert control over their environment has existed since the beginning of civilization. In recent years, this concept has been labeled "self-determination." Self-determination refers to an intrinsic drive to be the primary determiner of one's thoughts, feelings, and behaviors. The potential to be self-determined exists in all individuals regardless of severity or type of disability. While individuals with more severe disabilities may need significantly greater supports and may be capable of exercising personal control over fewer aspects of their lives than persons without disabilities, the motivation to be self-determined is present in all human beings.

> ...striving to attain self-determination doesn't begin (or end) during adolescence or early adulthood. Rather, it is initiated shortly after birth and continues until we have breathed our last breath.

Self-determination may involve, but is not synonymous with, independence and autonomy. Rather, it entails the individual him/herself determining in what contexts and to what extent each of these behaviors/attitudes will be manifested. A sense of self-determination is necessary for the development of individual identity and is a crucial catalyst of autonomy. It is closely linked to the manner in which we view ourselves, how we are perceived by others, and the quality of life we experience. Self-determination is equally important to persons with and without disabilities and is based on essentially the same processes for both groups. For a variety of reasons, however, children, youth, and adults with developmental disabilities often fail to exert control over their lives. As a result, upon reaching adulthood many find themselves living, working, and recreating in settings they did not choose and that do not reflect their preferences and/or meet their needs.

Will this current situation change in the near future? At this point, I am not optimistic because it would appear that we have taken an overly simplistic view of an extremely complex problem and have failed to consider a number of important elements that contribute to self-determination. What are some of the ingredients that we have forgotten in our "recipes" for self-determination? First, and probably foremost, is the notion that self-determination is a developmental process. By this it is meant that to attain personal control over one's life, an individual must develop and integrate a wide variety of skills, attitudes/beliefs, and knowledge over the course of a lifetime. It is not a short-term process that can be "crammed" into a few years, but an undertaking that is never complete. While it has thus far been treated as such, striving to attain self-determination doesn't begin (or end) during adolescence or early adulthood. Rather, it is initiated shortly after birth and continues until we have breathed our last breath. It doesn't merely involve the development of isolated skills, but entails the integration of these skills and their continual use and refinement in a wide variety of settings.

What does it mean to state that an individual's pursuit of self-determination begins shortly after birth? Most people view infants as helpless creatures who are totally dependent on their parents/caregivers for survival. Recent developmental research, however, suggests that this is not an accurate perception. At birth, most infants have within their behavioral repertoire the crying reflex. How is that reflex used? Do infants cry randomly, or is there a purpose behind this seemingly reflexive behavior? Thirty years of study clearly indicates that infant cries are purposeful - they are attempts to elicit the support necessary to change the child's environment. Within the first few months of life, specific "types" of cries develop to signal that the infant is hungry, angry/frustrated, or in pain. It is obvious that infants, in most cases, cannot bring about environmental "change" on their own. Rather, they are dependent on the support and caregiving of responsive adults. However, this does not alter the fact that the infant cry is an attempt of the individual, albeit at a very rudimentary level, to take some degree of control over the environment.

As a child matures, the "signaling system" and the behaviors it uses to initiate change (i.e., exert personal control) within the environment become more sophisticated. With the development of language, preferred objects and activities can be requested and those that are not preferred rejected. Think of the two-year old who seems to get much enjoyment from use of words such as "no" and "more." Is it mere coincidence that these are among the first words of so many children and used by them so frequently? Both of these expressions, along with maturing physical skills, allow the child to exert control over his/her environment. This control is, in and of itself, a powerful reinforcer. It is also during infancy and early childhood that children develop personal preferences with respect to everything from the proper way to eat an Oreo cookie to the colors and types of clothes they wear. The specific desires that children have may change, but from early in life these preferences guide behavior and contribute to their developing personalities.

The extent to which a child exercises self-determination is quite circumscribed during the early years. Because of limited skills and a modest knowledge base, the specific areas of life over which young children have control and the degree of control they are allowed to exert is typically quite narrow. It is, however, extremely important that all children be given some degree of control at this time of their lives. While the choices made may be simple and involve few areas, they are critical in that they provide the foundation for self-determination in later years. Through being able to direct their own lives in circumscribed areas, children are able to practice and refine those processes (e.g., choice-making, problem-solving, self-regulation of behavior etc.) necessary for self-determination as an adult. In addition, they are able to develop the knowledge base and belief systems that will motivate them to exert personal control.

While parental regulation is foremost during infancy and early childhood, during middle to late childhood children begin to take considerably greater control over their lives. This is a period of "co-regulation" or "collaborative control." During this developmental phase, children take primary control of moment-to-moment and day-to-day decisions while parents retain control over events and decisions that have long-term implications. The impetus for this change is quite simple: children are spending the majority of their time in school or associating with peers. As a result of decreased contact with parents, children, almost by default, exercise greater control over their lives.

> ...to attain personal control over one's life, an individual must develop and integrate a wide variety of skills, knowledge, and attitudes/beliefs over the course of a lifetime.

Increased contact with peers and decreased interactions with parents during middle to late childhood facilitate self-determination in a variety of ways. By definition, peers are individuals of approximately equal authority. Interactions with members of peer groups are therefore likely to have considerably more "give-and-take" than those with adults. As a result, such relationships present excellent opportunities for adolescents to refine self-determination skills, experience the consequences of their choices, learn from mistakes, expand [illegible] knowledge base, and receive reinforcement for exercising personal control. In relationships with adults this is much less likely to occur due to the imbalance in power.

Entry into adolescence and the impending onset of adulthood typically results in further changes in the degree of personal control individuals exercise over their lives. As youth and young adults begin to demonstrate the capacity to successfully exercise self-determination, they are typically afforded opportunities to take greater control over aspects of their lives that have long- and short-term implications. This is the period during which individuals begin to generate and refine their personal visions for the future and come to rely on significant others to provide support rather than to make choices and decisions for them. As young adults move away from home and establish themselves within the community, decreased contact with parents and other family members presents opportunities for individuals to assume greater personal control. Young adults are aided in this process by the many rituals that accompany important transitions at this time of life. These rituals (e.g., graduating from high school, getting one's drivers license, reaching "majority" age) signal to family members and society in general that adulthood has been attained and, for most individuals, that the person will assume increased personal control.

Self-determination and related efforts to exercise personal control remain a driving force throughout adulthood. Self-determination skills are refined and the individual learns that one's approach to gaining personal control needs to be at least somewhat situationally specific (e.g., advocating for oneself in a somewhat different manner with friends as opposed to a work supervisor). One's knowledge-base increases as the person learns not only about how systems work, but how to get what one wants, needs, and/or is entitled to from service systems. Adulthood is also a time during which beliefs and values related to the assumption of personal control (e.g., individuals' perceptions that they have the capacity to control their lives) are solidified. During the adult years many individuals also continue the process of attempting to achieve a balance between self-determination and interdependence with others. It is only when such a personally defined balance is realized that there will be established a symmetry between one's desire for self-determination and the need to be a part of a social group.

As an infant with a developmental disability matures into a child, adolescent, and finally an adult we, as professionals and family members, can do much to support that individual's self-determination. The realization that the process is a complex lifetime quest rather than a short-term "adjustment" is a first step in this direction. Ensuring that all persons, from infants to adults, have the opportunity to direct their own lives will not be easy. Whether one is a parent, other caregiver, sibling, or professional it is often tempting to make choices and decisions for others about whom one cares. However, through keeping our vision focused on desired long-term outcomes for the individuals with developmental disabilities with whom we are involved, we can begin to develop ways to facilitate their exerting a degree of control over their lives with which they are satisfied.

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Facilitating Self-Determination Through Early Intervention

by Ann Eggebeen and Annetta Leigh

As children grow and develop, they increasingly make a wider range of choices and take more control over their lives. These choices range from an infant who by crying lets a caregiver know that he/she is hungry, to a teenager making choices about post-secondary education and careers. Infants express their preferences by smiling, vocalizing, crying, clinging, and cuddling, among other ways. Toddlers definitely express their preferences by saying "no" and "mine", running the opposite way their parents want them to go, and spitting out food they do not like. Preschool-age children are able to label their feelings, and develop an even greater desire to establish control over what they eat, when they sleep, and what they wear. Parents play a major role in the development of their child's self-determination by facilitating the making of choices by the child and supporting the child's drive to take more control over his/her life.

Early intervention professionals can assist parents to foster self-determination in their children with disabilities. This can happen in many ways. During infancy, the professional can assist parents with reading their child's cues, particularly with infants who have a physical disability, sensory impairment, or are "difficult babies." They can work with parents in identifying the manner in which a child communicates pleasure, displeasure, the need for attention, and the need to withdraw in order to regroup before interacting. For a child who is difficult to quiet, the professional can serve as an objective observer and help identify ways, times, and techniques to help the child become quiet.

As the infant matures and expresses a greater interest in the world around him/her, the early intervention professional can introduce the child and family to ways of facilitating these interactions. This could include the use of adaptive switches on battery-operated toys to help a child with a physical disability develop the concept of cause and effect. Proper positioning for the child to be able to reach and grasp for objects, maintain head and body control, or increase the lung capacity to facilitate speech are other ways that early intervention professionals can help a family increase a child's self-determination.

As a child without a disability becomes a toddler, the child increasingly exercises the option to make choices and persists in attempts to control the environment. The child with a disability should also have the option to make similar age-appropriate choices. Early intervention professionals, using their knowledge of child development, can assist parents in identifying appropriate choices for their child and assisting that child to communicate those choices. For example, professionals can help parents observe and identify the cues a child uses to express choices. They can help parents facilitate their child's increased exploration of the world around them and the ability to manipulate toys. This can be done by accessing equipment to facilitate independent mobility or by using developmental steps to facilitate muscle strength for mobility. Identification of alternative means for communication, where necessary, also facilitates the child's ability to communicate choices.

In the preschool years, the circle of the child's world widens and the child become increasingly involved with groups of same-age peers. Early intervention professionals can assist children with disabilities and their families at this age by offering suggestions for community involvement, such as Early Childhood Family Education classes, preschools (if not already enrolled as part of their special education programming) or play groups.

Early intervention professionals who work in classrooms can assist children with disabilities to exercise self-determination by physically structuring the environment, providing appropriate materials, and structuring the classroom routine to facilitate choice making. Physically structuring the environment involves setting up a safe environment where materials are easily accessible to children and movement around the classroom is not hindered. Providing appropriate materials includes having adaptive equipment available, as well as a variety of materials that are age-appropriate for children and provide a stimulus for engagement in different types of play. Structuring the classroom routine to facilitate choice-making includes providing a wide variety of experiences so that children can make informed choices and, as much as possible, giving children a say in the classroom routine. These could include demonstrating how new toys work before giving them to the children, organizing field trips to new settings, and allowing children to choose the classroom jobs each will do for the week.

Early intervention professionals have the opportunity to play an important role in facilitating the self-determination of children with disabilities. By supporting families' efforts to encourage children to assume a developmentally appropriate degree of personal control, professionals provide a foundation upon which future skills for independent living and community involvement will be based.

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Daily Self-Determination for Young Children

by Jean Mendenhall and Marijo McBride

Self-determination is about making choices and being in charge. Children learn about self-determination through a combination of what others do to, for or with them, and how others respond to their actions and expressions of feelings and ideas. Family members, friends, and caregivers have daily opportunities to shape a young child's sense of self-determination. Those opportunities include the following:

- As adults share their own interests with children - such as going fishing, visiting a museum, or decorating a cake - they support self-determination by teaching children the rich variety of options open to them.
- Respecting children's choices about what clothes to wear, which toys to play with, and how to be comforted helps develop their sense of identity and control.
- Giving the child what has been asked for (a drink of milk, a game of hide-and-seek, a hug) and stopping immediately when the child says "No" or "Stop" teaches the child that his/her needs and wishes are important and can be fulfilled.
- Even when the response to a child's request or choice is "no", it can be handled in a way that supports the child's sense of self-determination by acknowledging the child's communication ("I hear that you want...") and conveying acceptance of the feelings.
- Some disabilities may make it more difficult for a child to go places, do things, express feelings or convey choices. When this is the case, it becomes all the more important to start early and work conscientiously to build these capacities. This may include using assistive technology to support self-expression and choice-making.
- Sometimes a child's communication attempts are understood by only a few people in his/her life; it is important to assure that someone is present, no matter where the child is, who can understand or interpret the child's communication.

Lastly, families can support self-determination in young children by having dreams and visions for the child and for themselves, and then identifying ways to support those dreams. Creating dreams and visions becomes an ongoing process, a treasure hunt of possibilities and capacities. And the fulfillment of those bigger life dreams begins with simple daily support for the child's sense of self-determination.

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Raising Rachel

When we brought Rachel home from the hospital in 1983, we did not consciously decide to raise our daughter any differently because she had cerebral palsy. We assumed, based on "learned medical opinion", that she was severely retarded and would not progress much beyond where she was at birth. Still, we took a positive approach and began to introduce her to the world around her: colors, shapes, sounds. Soon, we noticed that Rachel was aware of what was going on around her and so we continued. We worked at the same things parents of nondisabled children do, we just worked a little harder, a little longer, and threw in some early intervention services for good measure.

As she grew, we let Rachel know the circumstances surrounding her birth by showing her pictures and talking to her about what happened. We have been painfully honest with her about what it means to have cerebral palsy - both the bad (the physical limitations) and the good (close-up parking spaces during the Christmas shopping frenzy). It never mattered that we didn't know how much she understood; we just kept talking and hoping that she understood even a little of what we were telling her.

Today we take Rachel everywhere. She has learned to shop for her own clothing, to make color choices, to match patterns. She is expected to show respect to others and to use good manners. She is given the opportunity to make choices and contribute to family decisions. We let her make mistakes and then try to guide her to the right solution. We hold her responsible for the decisions that she makes. In short, we have raised her the same as we would had she been born without a disability.

It is hard to raise a child to a secure adulthood these days. Throw in the exceptional medical and educational demands that a disability brings with it and things get down-right impossible at times. But, by staying focused on one's hopes and goals, it is possible to parent successfully and not lose one's mind in the process. Today, Rachel thinks of herself as a nondisabled person who happens to use a powered wheelchair to get around, a computer to talk, and who has a lot of friends to help her do the things her hands cannot. Her cerebral palsy is just a label, something that gets in the way of being Rachel.

By Ann Esparza who, with her family, lives in Mendota Heights, Minnesota.

Self-Determination as an Educational Outcome

by Michael Wehmeyer

Among educators and educational researchers there is a growing awareness that a key ingredient of educational success is missing from the educational experiences of many students with disabilities. Educational success for such students is increasingly being measured by the attainment of adult outcomes such as gainful employment and community involvement. Because far too many students with disabilities are not attaining these, we must look further for factors that contribute to educational, and thus adult, success. One such factor is self-determination. In fact, Halloran (1993) identified self-determination as "education's ultimate goal."

For purposes of education, self-determination is best conceptualized as an outcome, a set of attitudes and abilities learned across the lifespan that are associated primarily with achieving adulthood and fulfilling adult roles. This article examines self-determination as an educational outcome, exploring educators' roles in its promotion.

■ Characteristics of Self-Determination

Self-determination refers to the attitudes and abilities necessary to act as the primary causal agent in one's life, and to make choices and decisions regarding one's quality of life free from undue external influence or interference. Self-determined individuals act autonomously, and are self-actualizing and self-regulating. Causal agency implies that it is the individual who makes or causes things to happen in his/her life and that a given action was purposeful or performed to achieve an end. It is a critical element contributing to an individual's quality of life, across settings, environments, and opportunities.

Attitudes contributing to self-determination encompass personal perceptions and beliefs about oneself and one's control in the environment that have an impact on the degree to which one is capable of becoming the primary causal agent in one's life. Personal perceptions about oneself include: (1) self-awareness - the capacity to think in terms of self-concepts (formed through experience with and interpretation of one's environment and influenced by evaluations of significant others, reinforcements, and attributions of one's own behavior), and to focus attention, process information, and act in relationship to these conceptualizations; (2) self-esteem - a sense of personal worth and competence based upon self-evaluations expressing an attitude of approval or disapproval and indicating the extent to which an individual believes him or herself to be capable, significant, successful and worthy; and, (3) self-confidence - certainty in oneself and one's abilities, feeling sure or having faith in oneself and one's abilities without conceit. The attitudinal components incorporating one's perceptions about control in one's environment involve: (1) self-efficacy - a sense of personal mastery over one's environment and the expectation that one can successfully execute behavior(s) required to produce a specific outcome or outcomes; (2) outcome expectancy - an individual's estimate that the performance of a specific behavior will lead to a predetermined outcome; and (3) locus of control - the degree to which a person perceives contingency relationships between personal actions and outcomes, encompassing how an individual views reinforcement in his/her life (as primarily the consequence of one's own actions or as the result of outside forces).

Abilities contributing to self-determination consist of skills and proficiencies that enable one to become the primary causal agent in one's life and to make choices about one's quality of life. There are a number of such skills, but some are "core" and appear as components of most interventions to promote self-determination. These include the ability to make choices and decisions; to identify alternatives, recognize consequences, and locate resources to act upon decisions; problem identification and problem solving skills; goal attainment skills such as learning to set realistic, achievable goals and objectives; and self-organization skills. To promote the development of personal efficacy and self-awareness, individuals need to learn to recognize and identify physical and psychological needs, how these are met, and how they influence actions.

■ Education's Role in Self-Determination

Ensuring that students with and without disabilities are self-determined will be as complex and difficult a process as comparable efforts to ensure that students with disabilities attain gainful employment or community involvement. It has become increasingly obvious that an educational program that adequately promotes self-determination will not consist of unilateral efforts that only change curriculum, create peer mentor programs or structure environments. Instead, an effective educational emphasis to promote self-determination will encompass a host of alterations and adaptations as well as parallel emphasis in the student's home and community. Appropriate, functionally-derived curricula; environments that enhance opportunities to experience choice and to express preferences; interactions with peers without disabilities; access to adult role models; experiences with success; and control in decision-making all contribute to the eventuality that a student will become self-determining. In addition, it is clear that educational efforts to promote self-determination must span the student's learning experience.

Educators play a critical role in development of self-determination or the lack thereof. Unfortunately, the latter is too often the case. The need to structure the special education classroom to meet educational, behavioral, and administrative requirements may result in an environment promoting dependence and limiting choice and decision-making.

Teacher recognition of the importance of skills related to self-determination is the critical first step in promoting self-determination. If not already a focus for educators, there are a number of skills that are essential to becoming self-determined and which warrant instructional attention. Examples of these skills include learning how to access resources, communicate preferences, set achievable goals, plan and manage use of time, identify and solve problems, self-advocate, and, for some students, make choices. In addition to instruction in such skills, the methods and strategies teachers adopt can facilitate the acquisition and utilization of self-determination skills. Instructional models such as role-playing and self-control are effective methodologies for promoting autonomy and self-determination. The use of other strategies, such as relaxation training, metacognitive instruction, and brainstorming, while typically underutilized with students in special education, would also seem to hold promise.

Skill development goes hand in hand with the promotion of attitudes and perceptions critical to becoming self-determined. To enhance motivation and encourage self-determination, teachers should provide activities that optimally challenge the student. Educators can promote autonomy by supporting student initiation of activities and allowing choice. Of particular concern here is the control orientation of the teacher. Students with cognitive disabilities need to learn that they are causal agents for their own lives. Excessive external control is detrimental to this. Students need to be provided opportunities to express preferences, make choices, and then experience the outcomes. Recent efforts have focused on the Individual Education Plan (IEP) process; students can learn to assume more control and responsibility in their IEP, identifying and prioritizing goals or objectives, and taking a leadership role in the meeting.

What can educators do to promote expectations of personal competence and efficacy? Generally, success raises efficacy expectations. However, even within the experience of failure, the perception of progress can lead to expectations for success. A primary means of indicating success or progress is through verbal feedback or reinforcement. Positive feedback needs to be administered in a context and and manner that is non-controlling, but honest. Students need to be provided rationale for the performance of activities, as well. Teachers should not leave choice to chance. They must plan for ongoing opportunities to make choices.

Finally, the educational process must empower the student and his/her family to become active, equal partners in educational planning, and must enable students to invest in their own futures by taking advantage of educational opportunities. The Individuals with Disabilities Education Act (IDEA) now requires that student preferences and interests be a part of the transition planning procedure. Educational personnel must not only reach out to involve parents, siblings, and students, they must set the stage such that real control is shifted to these team members. Educational practices that strip the student of the perception of control will serve only to alienate students further from the process and limit self-determination. Perhaps the most flagrant violations in this regard involve the assessment process. The special education enterprise has been built on a deficit-based identification process during which professionals diagnose problems through testing and assessment procedures that rarely involve the student as a contributing member. In fact, the process often requires that the student remain unaware of the intent of the test.

On the other hand, no individual is completely autonomous or self-determined. This is even more applicable when one is talking about children or adolescents. Transferring control and responsibility to students involves instruction, structure, and support. Simply removing all previous structure is nothing more than an invitation to anarchy. Teachers, administrators, parents, related service personnel, and students need to work together.

Although many skill areas related to self-determination are more applicable to older students or students with mild disabilities, self-determination is not the sole domain of secondary education or students with mild disabilities. Making choices, indicating preferences, and developing self-awareness and confidence involve lifelong experiences and instruction, independent of level of disability. There are normative developmental courses for children's understanding of causality and the development of self-concept and self-awareness. Thus, while adolescence is a critical period for the development of many skills related to self-determination, instruction during elementary years also needs to nurture experiences conducive to these achievements.

As is illustrated by this brief discussion, education's role in the development of self-determination for children and youth with disabilities is critical. There are curricular, methodological, and attitudinal orientations that promote self-determination, and these need serious attention from the educational community

Michael Wehmeyer is Research and Program Specialist in the Department of Research and Program Services at The Arc (formerly Association for Retarded Citizens of the United States), Arlington, Texas.

Reference: Halloran, W.D (1993). Transition services requirement: Issues, implications, challenge. In R.C. Eaves & P.J. McLaughlin (Eds.). Recent Advances in Special Education and Rehabilitation (pp. 210 - 224). Boston: Andover Medical Publishers.

Self-Determination: A Means to an End

by Michael J. Ward

In all of my writing during the past five years, I have emphasized the need for education to focus on facilitating the development of self-determination skills so that individuals with disabilities can define goals for themselves and take the initiative in achieving those goals. It has occurred to me recently, however, that my emphasis on the need for education to focus on the skills necessary for self-determination has been short-sighted!

Self-determination is a process and characteristics such as empowerment, assertiveness, decision-making, goal-setting, and self-advocacy are skills that are taught through this process. Can an individual know empowerment skills and not be empowered? Can a person understand assertiveness and not be assertive? Can someone have decision-making skills, but not be able to make a decision? Can someone practice advocacy skills and still not be a self-advocate? The answer to all these questions is YES! What is missing is our focus on desired outcomes.

If self-determination is a process, then the desired outcomes must be to prepare youth to be self-determined, empowered, and assertive and to make decisions, set personal goals, and advocate for themselves to ensure that their needs are met. Even this misses the mark because the question then becomes, to what purpose is someone empowered, assertive, self-advocating, and able to make decisions? Therefore, the optimal outcome of the self-determination process is the ability to set and achieve meaningful goals. These goals must facilitate maximizing one's potential and include working in a gainful and satisfying job, living as independently as possible, having friends and relationships with significant others and participating in the community activities one chooses.

If education is to focus on teaching self-determination skills so that students with disabilities can define goals for themselves and take the initiative in achieving those goals, it must also be involved in helping them achieve some of the initial goals that will maximize their potential. Educators must ensure that students take action in setting and achieving self-determined goals.

Self-determination can be viewed as a complex process. As the individual strives to become self-determined, there are many more obstacles acting as barriers to their exercise of personal control than working to support them. To fully understand the path to self-determination it must be remembered that each individual is unique with his/her own set of characteristics. The forces driving and motivating the individual towards self-determined goals are conceptualized as both external and internal to the individual. There are also unknown factors that result in individuals being self-determined against all odds.

What do educators need to know to facilitate the self-determination process? The process of teaching skills necessary for self-determination should be time-limited. We should decide together with students how long they need to be in the process before they are self-determined and the process is completed. However, students should be encouraged to set and achieve goals anytime during the process whenever they feel that they can do so.

We can also ensure that the playing field is level. Youth with disabilities should be able to select the goals toward which they want to work. As educators, however we have the responsibility for not making the process for attaining goals more difficult than it needs to be. We have the responsibility for making students aware of the specific obstacles they will face. We can also increase students' chances of success by identifying and providing the necessary supports.

Through the educational process, one can have a great impact on the extent to which students with disabilities develop the necessary skills and supports for self-determination. Although some of the factors that facilitate self-determination with specific individuals may never be identified, comprehensive and appropriate assessment has the potential to help. Students must become aware of those factors that work in their favor and allow them to capitalize on their strengths. Students also need to be aware of barriers or obstacles to self-determination so they can learn how to compensate. Self-determination instruction, for example, can attempt to develop other skills that will intrinsically guide students toward their chosen goals.

Self-determination is just one of the many processes encompassed by education. It is a means to an end. We need to scrutinize each of these processes, whether it is physical therapy, vocational assessment, a functional skills curriculum or inclusion and ask whether it will lead to meaningful and self-determined goals. If there is data that indicates that the process does not lead to meaningful and self-determined goals, it should be modified, combined with a more effective process, or abandoned altogether. In our efforts to improve the outcomes of the education of children and youth with disabilities, we should never be reluctant to admit that the "en vogue" process may be short-sighted. It is only by focusing on meaningful and self-determined goals that maximize one's potential that education will foster improved outcomes for youth with disabilities.

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MAPS: A Strategy for Promoting Self-Determination

by MaryBeth Doyle, Jennifer York, and Robi Kronberg

At a very early age children begin thinking about what they want to be and where they want to live when they grow up. As they mature toward adulthood, certain visions of the future take on more significance than others. During middle school or high school, some young adults begin to integrate their past experiences with their knowledge of personal strengths and weaknesses in order to more fully explore aspects of their visions of the future. As this begins to happen, students make more deliberate choices about specific learning opportunities that will increase the likelihood of the vision becoming reality. These choices may be related to a specific course of study, internships, community volunteerism, or interpersonal relationships. During this time, adults - typically parents and teachers - play an important role in supporting the young person's movement forward by providing advice, support, and feedback.

Research and personal experience indicate that students with disabilities of all ages and levels of severity have the capacity to contribute significantly to the development of both short- and long-term goals and that their motivation to attain personally set goals is quite high. Unfortunately, many are not given the opportunity to develop personal visions of their futures. When such visions are developed and communicated to others, they are often ignored during the course of program development and implementation, with the "real decision-making" delegated to professionals who are thought to have "special skills and insight."

One strategy that is often used to support students in creating the dream for their future is the McGill Action Planning System (MAPS) (Forest and Lusthaus, 1987). MAPS is an affirming planning process that begins with a committed group of adults and peers coming together to think creatively about the future with a specific student. It is based on the assumptions of inclusion in the community, individualization, central involvement of friends and family, collaboration, and flexibility. The MAPS process is a facilitated discussion organized around seven questions:

- What is ________'s history?
- Who is ________? How could s/he best be described?
- What is ________'s dream? What would s/he like to be? Where would s/he like to live? What types of relationships does s/he want in his/her life?
- What is ________'s nightmare?
- What are ________'s strengths, gifts, abilities, capacities?
- What are his/her areas of need?
- What would an ideal day look like? How does the information that has been shared today relate directly to the daily schedule?

The MAPS team is composed of the student and people who are most significant in the student's life. Generally included are a few of the student's close friends and classmates, family members, teachers (general and/or special), and anyone else who is committed to joining in the creation of a desirable future with the student.

Also included in the MAPS session are a facilitator and recorder who participate by posing the questions and capturing information. The facilitator sets the tone for MAPS to be an affirming and hopeful process by creating a safe climate and sense of community. This person brings participants together to focus on their common goal of envisioning a desirable future with the student. The facilitator introduces each of the MAPS questions and then solicits participation of the student and each member of the team.

The MAPS planning process takes two to four hours and is usually facilitated in two sessions. During the first session, the discussion is focused on envisioning a desirable future with the student. During the second session, the focus shifts to identifying what needs to be done, by whom, and within what timeframe in order to realize the vision. It is recommended that MAPS be conducted prior to and in preparation for major transitions, (e.g., segregated class or school to an inclusive class or school, elementary to middle school, middle school to high school and high school to adulthood). These times are natural breaks when students and family members reflect on past experiences and their hopes and dreams for the future.

Given the reality that we cannot teach students everything that they need to know, taking the time to dialogue about what constitutes a desirable future will increase the likelihood of students with disabilities choosing the most relevant current learning opportunities. This philosophy and the MAPS process not only allow a student to create a personal vision for the future that can serve as a roadmap, but have the potential to help the student develop the necessary supports to eventually arrive at the chosen destination.

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Transition and Self-Determination: Putting the Promise into Practice

by Sandy Thompson and Stephanie Corbey

Throughout the United States, the "promise" of consumer planned transition has now become law. On the basis of that promise individuals with disabilities are to plan during high school for a successful adult life, with support as needed. This represents a tremendous and difficult change for teachers and service providers who have been trained to make decisions for, not with, students with disabilities, and who have traditionally planned for graduation, not beyond.

Under current law, as articulated in the Individuals with Disabilities Education Act (IDEA), consumer-planned transition is:

> ...a coordinated set of activities for a student, designed within an outcome-oriented process, which promotes movement from secondary school to post-school activities...This coordinated set of activities is based upon the individual student's needs, taking into account student preferences and interests, and includes instruction, community experiences, the development of employment and other post-school adult living objectives, and acquisition of daily living skills and functional vocational evaluation.

IDEA goes on to mandate that students be invited to their own Individual Education Plan (IEP)/transition planning meetings. If the student chooses not to attend, his/her preferences and interests must still be considered. As can be seen by this definition, transition is a process, one that is most successful when determined by the person in transition. Well, that is the promise, but how can it be put into practice?

Most transition planning procedures focus on the roles of parents and professionals with little attention given to the role students with disabilities themselves must play in their own transition process. Involving students in making decisions about their own lives is extremely important. A person who is an active participant in the planning of his/her future is more likely to be committed to making those plans work. Each student needs to be encouraged to articulate his/her life vision or dream, determine current strengths and challenges, establish goals, design plans to attain those goals, express preferences, and follow through on activities that lead to successful adult outcomes.

In Minnesota, we have been working on designing a practical approach to preparing students with disabilities for their transition to adult life. This process involves several steps, with the student as the focus of each step. Central to this process is the development of a transition plan. A transition plan accurately describes a student's current situation through assessment, assists a student in developing a clear and positive vision of the future, identifies specific skills that are needed to meet this vision, and sets up opportunities and supports that will make the vision a reality using IEPs and other formal planning documents. In Minnesota, the transition plan is incorporated into the IEP.

The IEP meeting is one critically important and appropriate place for the student to have an active, and self-determining role. What is being discussed and planned in the IEP meeting, after all, are services that will directly affect the student's life, now and in the future. To facilitate the student's participation in the transition process, however, many students may need to be informed about the nature of their role in the IEP meeting and afterwards - specifically, what their participation entails. Expressing personal preferences and desires, and advocating for themselves - particularly in the presence of "authority figures" such as administrators, teachers, and parents - may be a new role for students, one for which they need guidance and feedback. Teachers and parents can help prepare students to participate in their IEP meetings by talking about its purpose, describing what goes on and who typically attends, and discussing transition issues before and after the meeting occurs. Some students may benefit from rehearsing certain aspects of the meeting (e.g., greetings, appropriate ways to express preferences or suggest alternatives). If a student requires any accommodation, such as an interpreter or an augmentative communication device, this should be arranged (by the student, parents, or teacher) in advance of the meeting to remove any artificial obstacles to the student's participation. Ultimately, the goal is for students to assume control (with appropriate levels of support) over their transition program and identify and manage its various components.

Hopefully, there will soon come a day when students and their families are central in the development of post-school plans. This self-determination, however, cannot begin when a student reaches the age of 14. It is a way of thinking that begins early in childhood when children begin discovering their interests and making decisions in their lives. A successful transition is only the culmination of this lifelong process.

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People First Facilitates Student Self-Determation

by Ruthie Beckwith

Students with disabilities in high school face many challenges. In addition to completing their basic coursework they must learn to navigate their way through changing relationships with parents, teachers, and peers. They must master complex tasks and come away from high school with a plan for taking their place in the community as adults. Many people refer to the process of preparing for adult responsibilities as "transition." Additionally, the process of considering and deciding what one's place will be is one aspect of what is called "self-determination."

Three years ago in Tennessee adults with disabilities had the opportunity to interact with transition-age students at a local sheltered workshop. These adults were active members of a local People First chapter. Through this interaction, these adults recognized a need for younger people to be collectively exposed to the concepts of self-advocacy and self-determination. They shared this view with the state People First organization and adopted the development of high school People First chapters as a statewide goal.

Funding from the U.S. Department of Education has provided a unique opportunity to implement a statewide project designed to help high school students learn self-determination skills. A key component of this project is the formation of high school chapters of People First. These chapters are considered "clubs" in the same way as any other high school activity, and membership is open to any student whether or not they have a disability. All activities designed to address and teach self-determination occur during club meetings. To date, 260 students with disabilities have been part of the project based in 13 high schools across the state.

People First's basic philosophy is that all people can learn to speak for themselves, regardless of their disability or its significance. People First also believes that group self-advocacy is one of the most effective ways to empower people to speak for themselves as individuals and as a collective body. Students in the high school groups are introduced to this process of empowerment through the development of skills in leadership, meeting participation, decision-making, and planning.

Club members elect their own leadership, set agendas, identify group goals, and plan and carry out projects in their school and communities. At the same time, they receive instruction in how to make plans for their own futures. Instruction related to self-determination skills is based upon issues that are important to high school students. These issues include those related to disability (e.g., acceptance, accessibility, rights, responsibilities) as well as social issues (e.g., AIDS, sexuality, and drug abuse).

As club members have graduated and moved on to adulthood, many have stayed in contact with their high school clubs or formed "alumni" chapters. The challenge that lies ahead for the project is to develop better strategies to help these graduates remain involved in People First.

Self-advocacy and self-determination are lifelong processes. Collectively, people with disabilities can use these processes to create a world of opportunities for themselves and their communities.

Ruthie Beckwith is Project Director with the Self-Determination Project, People First of Tennessee, Nashville.

Getting Beyond "Yes": Holly's Story

In high school the only way I thought I could help myself was if I did everything the way the people who wrote my Individual Education Plan (IEP) told me. I was made to feel like everyone else knew what was best for me; the support team knew what computer I should use, what my schedule should be, and what my social life should be like. Meanwhile, it seemed like the only word in my vocabulary was "yes." I let other people make all the important decisions in my life.

Fortunately, I had a very good friend in high school; I could tell her what I thought. She was the one who told me that I needed to start speaking up for myself. She made me realize that I had some important and valid opinions. After this, I made people listen to my decisions and also act on them. I gradually began writing my own IEP goals, putting emphasis on things I thought were important. Things like getting good grades and developing contacts for assistance while I was in college were more important to me than my physical independence. By the time I was a senior in high school, I was pretty much taking care of all the major decisions in my life.

One of the contacts I made during that last year in high school was with the Metropolitan Center for Independent Living (MCIL). The people there, along with my IEP team, assisted me with the transition from high school to college. MCIL taught me a little bit about dealing with personal care attendants (PCAs) and the local paratransit system. After this small amount of training, I went to college thinking that I could handle just about anything. But I didn't know what

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A New Era of Self-Determination

by Michael D. West, John Kregel, and W. Grant Revell

The importance of self-determination for persons with disabilities has finally been recognized by educational programs, adult services, and advocacy groups. With the Rehabilitation Act Amendments of 1992 (PL 102-569), self-determination has been transformed from a "good idea" to a legislative mandate for the federal/state Vocational Rehabilitation (VR) program. The 1992 Rehabilitation Act Amendments, like the 1990 Americans with Disabilities Act (ADA), signaled a new era for persons with disabilities and for programs and support services, an era of inclusion, equal protection, accommodation, consumerism, and empowerment. This article will describe key changes in the Rehabilitation Act that promote choice and self-determination for consumers, and issues that will arise as rehabilitation agencies attempt to implement the Act.

■ Eligibility Determination

Prior to the 1992 Amendments, the VR service system required prospective clients to undergo assessments for rehabilitation potential, employability, and feasibility for services. In many VR systems, this process prevented individuals with very severe disabilities from accessing services because VR counselors did not have a reasonable expectation that services would result in employment. Many individuals with severe disabilities who were accepted as clients found that their vocational service options were limited to sheltered employment.

With protection from discrimination and mandates for reasonable accommodation under ADA, and the availability of assistive technology, job coaching, and personal assistance in the workplace, severe disability is no longer analogous with limited potential for employment. Title I of the Rehabilitation Act [Sec. 121] states unequivocally that all individuals, regardless of the severity of their disabilities, are presumed to be capable of gainful employment in integrated settings, given the necessary services and supports. Consequently, rehabilitation agencies have the burden of providing clear and unequivocal evidence that an individual *cannot* become employed in order to make a determination of non-eligibility. For individuals with severe disabilities, these changes will likely improve access to VR services that enable them to attain vocational outcomes of their choosing.

■ The "Choice Amendments" of the 1992 Rehabilitation Act

Once deemed eligible for services, the VR consumer becomes a "full partner" in the rehabilitation process, and is so empowered by the Rehabilitation Act. The Individualized Written Rehabilitation Plan (IWRP) must be developed jointly by the consumer and his/her VR counselor, focusing on the consumer's career goals and specific job preferences. The consumer has the opportunity to choose from among service options, service providers, and methods, and documents in the IWRP how he/she was informed about options and participated in choice-making. Perhaps most significantly, the consumer is allowed to secure his/her own services, including using family members, friends, or coworkers as support providers as long as their functions are consistent with the IWRP. The IWRP must be developed using the native language or mode of communication of the consumer, who is provided a copy. Consumer involvement in VR policy and system change is also a key component of the 1992 Rehabilitation Act Amendments. VR agencies are required to establish State Rehabilitation Advisory Councils, with majority membership of persons with disabilities who are not employed by the VR agency. This council is responsible for, among other things, assessing consumer satisfaction with services and increasing consumer input in strategic planning for expanding and improving services.

■ Self-Determination in VR Programs: How Do We Get There From Here?

Since its inception, the legislative intent and programmatic focus of the VR program has been to assist individuals who need time-limited interventions, such as specialized equipment purchase, short-term training, or physical restoration, to enter or return to the job market. Only since 1986, when supported employment became a VR service option, has the program as a whole begun to address the needs of individuals with severe lifelong disabilities who require extensive training, accommodation, and support in order to remain employed. This was a major policy shift for the program, one that has been difficult for many state VR systems and personnel to implement. The VR program again faces a major policy shift with the Rehabilitation Act Amendment of 1992, from a guardian and dispenser of funds and services for clients, to a customer service paradigm where the consumer's goals, preferences, and choices are paramount.

The U.S. Department of Education has released for public comment a number of proposed regulations for implementing the Rehabilitation Act Amendments of 1992. Comments regarding the choice amendments were solicited prior to release of the regulations, and as of this writing the final regulations have not been released. At this stage, the requirements and procedures that will be placed on state VR agencies in this critical area are pending.

There is much that VR agencies can and will do to promote self-determination, including (a) training counselors and supervisors on new choice regulations and procedures; (b) developing consumer and family orientation packages on consumers' right to choice; (c) incorporating choice and self-determination monitoring mechanisms in vendorship contracts; (d) compiling outcome data on services and service providers that can be used by consumers and family members to make informed choices; (e) developing new consumer assessment strategies that focus on consumers' values, objectives, and preferences; and (f) building sufficient flexibility into service options to allow consumers incremental opportunities to learn more about their work values and goals, such as job exploration programs and the freedom to leave a job without jeopardizing VR case status.

Ultimately, however, achieving self-determination will be the responsibility of consumers themselves. As youth with disabilities prepare for the transition from educational to adult services, they and their families members and advocates will require information regarding the right to access VR services and to participate fully in planning and choosing their vocational directions, VR-sponsored services and supports, and service providers. Training in self-advocacy will be essential for putting that information into action.

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From Assembly Line to Activism: Gloria's Story

When Gloria Steinbring moved from a northern Minnesota town to Minneapolis in 1968, she thought she was on her way to a new career: "My social worker in Hibbing told me that I should get job training, and Minneapolis had schools for this." Gloria had a natural talent for working with children, and dreamed of one day working in a day care facility. Upon entering the job-training center she had been told about, Gloria was "evaluated." "They said I couldn't get a competitive job," said Gloria, "because the dexterity in my fingers was not quick enough. They said, 'you can't work in a competitive job, so therefore you have to be placed in a long-term sheltered workshop. And you have to stay there for the rest of your life.'"

Although Gloria hoped to develop her skills as a child care worker, she was assigned rote tasks on an assembly line. "I used to put hooks in straps, hour after hour, all day long. I also sealed thermostat covers in a plastic package. I didn't like this work because this wasn't where my expertise was. This work made me feel like I was good for nothing," she recalls.

During the early 1970s, Gloria's sheltered workshop did not have enough work so she applied for a dishwasher job at a restaurant. "I was hired to scrub pots and pans on the graveyard shift," said Gloria. After four months of working nights, she was let go. "It wasn't a good match for me. They paid me a fair wage, gave me a free meal, and were nice to me, but I wasn't really fast enough."

In 1975, Gloria met staff from a local Arc and through them learned about self-advocacy. "People [illegible] the sweatshop kept saying 'You'll have to work here the rest of your life.' They kept pounding that into you," recalled Gloria. "When I began going to self-advocacy meetings, I learned that I had rights, and that I could stand up for myself. I thought, "The workshop is treating me like a kid, and I don't want to be treated that way."

As Gloria continued to attend self-advocacy meetings, she gained the confidence and encouragement to challenge her service providers. After 11 years at the workshop Gloria asked her social worker for an independent evaluation. The evaluation revealed that not only was she capable of working in competitive jobs, but was very capable of working in child care.

When Advocating Change Together (ACT) – a self-advocacy organization in St. Paul – was formed in 1979, Gloria decided to quit the workshop and join ACT as a volunteer, using her talents as a speaker to advocate for others with disabilities. Gloria's career since 1979 has been as an ACT board member and a self-advocacy leader. She is still interested in the conditions at workshops: "They've improved since I was working there. People are working in the community more. But we have a long way to go. Workers should be given a chance at the jobs they want. The attitude of the people running the workshops hasn't changed. Instead of telling people 'you can't do that type of work,' they should say 'you can.' "

As a national leader in self-advocacy, Gloria is pursuing her dream, speaking at the state legislature and national conferences, and appearing on talk shows. Working with people who appreciate and respect her does not include a paycheck, but Gloria certainly is having a positive influence on fellow self-advocates. She is motivated by her belief that, "We all belong in the community. We belong together."

By Gloria Steinbring, Vice President of the Board of Directors, and Jerry Smith, Communications Director, both of Advocating Change Together, St. Paul, Minnesota.

Guardianship and Self-Determination

by David Flower

The idea of legal guardianship understandably tends to raise mixed feelings in persons concerned with issues of self-determination. Guardianship is, after all, based on two premises seemingly irreconcilable with the ideal of self-determination. The first premise is that some people are not able to make competent decisions. The second premise is that those persons' legal rights to make certain choices should therefore be removed and given to another to exercise on their behalf. The dilemma concerning guardianship and self-determination is therefore quite clear: Guardianship is a legal relationship that attempts to insure that potentially vulnerable persons' best interests and rights are protected, but at the expense of the right to self-determination.

Legal guardianship is increasingly a thoughtful attempt to promote self-determination, rather than a simple taking away of rights.

Guardianship law, like our society in general, has traditionally been reluctant to view persons with developmental disabilities as capable of self-determination. There is a growing recognition, however, that historical assumptions about the capacities of individuals with developmental disabilities are simply not accurate. Legal systems are perhaps slower to change. Nonetheless, conceptions of "legal competence" and the roles and functions of guardians are also changing. The premises underlying guardianship are likewise changing in ways that may allow legal guardianship and self-determination to more peacefully coexist.

Guardianship laws increasingly recognize that individual capacity is not an all or nothing affair, to be determined simply by looking at a disability label. In the past, "competence" was often determined as if it were some inherent, global trait that most people were blessed with and some completely lacked. Most state guardianship statutes now require some degree of functional assessment of a person's capabilities and skills, rather than relying almost solely on a disability label to reach a conclusion of legal incompetence. Furthermore, most guardianship laws now acknowledge that decisional capacity is not global, but that a person may be able to make decisions in some areas or situations even if lacking capacity in others. Most states accordingly provide for limited guardianships, where the guardian is not automatically vested with plenary power, but may have a limited area of authority while the person under guardianship retains other decisional rights.

This increased focus on functional definitions of legal competence should also force courts to more clearly face the question of whether certain people need any sort of guardian at all. Indeed, the possibility of varying levels of need in regard to substitute decision-making relationships has brought increased interest to crafting a continuum of alternatives, including guardianship. Full guardianship should be seen as one option among many, including limited guardianship, alternative legal arrangements such as trusts and power of attorney, formal supports such as case management, and informal social supports. In this evolving view, guardianship is seen much as any other service: it may not be needed at all, and if it is needed it should be provided in the most appropriate and least restrictive manner.

There is also a growing understanding that not only is the ability to exercise personal control not a global, inherent trait, but that it is largely dependent on individual opportunity, social support, and personal growth. As people with developmental disabilities become part of communities, experience true opportunities for choice, and are supported in their choices, "legal competence" increases hand-in-hand with functional competence. To the extent that a person's choices and wishes are heard, valued, and supported by the larger community, there is less need for protective arrangements. Specific support tools such as personal futures planning reach toward this same end. The principles of support, not supervision; communication, not paternalism; and choice, not helplessness are coming to be valued in the practice of guardianship as they are in the ideal of community inclusion.

In this same vein, the role of legal guardians also seems to be undergoing some evolution. There is a move away from conceptions of guardianship as a custodial relationship, toward a view that guardians should serve primarily as "substitute decision-makers." In broad terms, of course, guardians have always been substitute decision-makers. Where the field of guardianship is truly changing is in a greater focus on the principles and processes of ethical decision-making. Substitute decision-making is seen less often as a paternalistic decision on behalf of the person, and more as a determination and advancement of the person's wishes. To some degree, the ideal role of guardians is converging on the role of advocates. Like advocates, when guardians truly hear and work to support a person's wishes, individual choice is supported. A guardian or advocate may be the only person who truly does hear and value those wishes, and can be instrumental in bringing them to a service system or community that may otherwise ignore them.

... the ideal role of guardians is converging on the role of advocates.

The changing nature of the services available to persons with developmental disabilities demands that we confront the dilemma of guardianship. The number and variety of options for work, community living, and provision of support services continue to increase. Service and support systems increasingly are taking on a market orientation, and state governments are encouraging privatization of services and emphasizing consumer choice. Given this trend, it is vital that important individual decisions do not devolve onto service providers or others who have no such legal or ethical authority. The first preference is always that the individual concerned should have true opportunity to make those decisions, and that individual autonomy receive support.

Most people with developmental disabilities can indeed exercise autonomy - a basic fact too long ignored. On the other hand, many do not exercise autonomy because of an inability or unwillingness of others to learn to communicate with them, a historical and still present unwillingness to offer the opportunity for choice making, and/or through the lack of community or social support. Legal guardianship is increasingly a thoughtful attempt to promote self-determination, rather than a simple taking away of rights. Like our communities in general, guardianship is an imperfect system that often serves to devalue and exclude some members of society. Like our communities, it is also a system in transition, and is slowly beginning to search for ways to support inclusion, autonomy, and dignity of all persons.

David Flower is a graduate student in Educational Psychology and a law student at the University of Minnesota, Minneapolis.

Making My Own Choices: Mike's Story

My name is Mike Williams and I am 24 years old. I live in a house with three other guys and I like them - they're all great. I've lived with them in this house for five or six years. A social service agency provides my roommates and I with the support we need to live here and do the things we want. I like the freedom I have here; I can come and go as I please. The staff basically let me do what I want. This lets me be my own person - an individual out in the community. I go shopping, to movies, and out to eat, and stay politically active in my community.

In the past, I lived in all kinds of foster homes where I wasn't given the opportunity to say or do what I wanted. Several years ago, however, I got involved in the Parent Case Management Project at Arc Suburban. This project provides tools to assist persons with developmental disabilities and their families to take an active role in determining the services they need and the way those services are delivered. Until I became involved in the Parent Case Management Project, I didn't know I had certain rights as an individual or that I could make decisions for myself. It is hard to make choices in your life if you haven't had the opportunity or are not treated with respect and dignity. I wouldn't want someone taking control of my decisions - that would frustrate me and anger me. I would feel like my rights were being violated.

For me, a good service provider lets persons with developmental disabilities be in charge of their lives. They do more than just pay attention to licensing requirements. They recognize when someone can make their own choices and let people give some input into the services they want. An exceptional service provider would let me walk into the office and say, "This is what I want, this is what I can do, and here is what I would like you to do for me." What it all boils down to is to let the consumer have choices about their jobs, and where and how they live.

The main way a service provider can meet my needs is by asking me what I want, and not assuming what I want. Service providers need to let each individual have choices as far as how they want their services provided. For instance, the agency that runs the house in which I live in has to deal with the state rules and regulations. Some of these rules and regulations are necessary, but some of them are archaic and unnecessary. They don't let service providers or consumers decide how they want their services delivered. There is so much paperwork to wade through to get even some of your needs met. Unfortunately, the process doesn't always allow for consumers to have their say in the decision-making process.

When it comes to self-determination, some people can't make decisions and others must make some decisions for them. A good service provider knows the capability of each consumer with whom they work. Every individual is given the opportunity to have some degree of self-determination. Providers need to work *with* individuals (i.e., consumers) instead of *for* them.

The most important aspect of self-determination for me is respect: Respect the individual, allow them to make choices if they are able and willing to do so, and then respect those choices. Ultimately, I would like to own my house and choose who works for me and what agencies and providers I hire. I hope service providers in the future will be able to support me in this dream.

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The Journey Toward Self-Determination

by Peter "Skip" Sajevic

People with developmental disabilities are finding greater voice in expressing what they expect in services and supports. These voices of growing empowerment say to professionals within disability-related fields, and residential services in particular, that people with disabilities want an active role in defining their places in the community.

Many years ago, it was commonplace and fashionable for local communities to appoint policymakers, advocates, and service providers to Residential Services Committees or task forces. In retrospect, the committees served a valuable function – for a time. They provided a forum for the community-at-large to be introduced to people with disabilities. They provided a force to change zoning laws. They attracted people to the field. However, they also communicated to the general public that "residential" placements were different from "normal" housing. Compounded by the scarcity of openings, the result was that people with disabilities were lucky to find community placements.

The messages were subtle, but understood. For families the message was, "Be grateful that you had *a* choice." For staff and providers, it was, "You must be special to take care of others." And for persons with disabilities the message was, "Do what you're told or you can be sent away." These messages have led to deeply rooted attitudes that present major barriers to persons with disabilities seeking alternatives. These attitudes persist even though most professionals involved in residential care understand the need to change the roles of staff and agencies. Additionally, the regulatory framework surrounding residential services is built on a foundation of protection and uniformity, often resulting in the dilemma of protection vs. the exercise of rights; control vs. the provision of opportunities; and treatment vs. experience.

In recent years, many initiatives have sprung up around the country to identify outcomes that people with disabilities want from supports or service programs. These initiatives hold in common continuous improvement and information-based practices that emphasize increased responsiveness to individual needs and personalized outcomes, as opposed to sanction-based, compliance standards. They hold the exciting promise that 1) the primary customer will be the individual with a disability, not the funder or regulator; 2) quality will be defined and measured in terms of personal satisfaction; and 3) all roles will be energized into active pursuit of meaningful results. This new approach will not only empower individuals with disabilities, it will also invigorate staff as they learn to assist individuals to create networks of support and community connections.

People with disabilities are gaining more access to and experience in our communities. They are making more decisions on where they want to live and with whom they want to live. Unlike in the past, people with disabilities today and, hopefully, in the future have more than *a* choice.

Peter "Skip" Sajevic is President of Nekton-Norhaven, a human services agency in St. Paul, Minnesota.

Leslie's Choices

My 34-year old daughter Leslie has autism and mild mental retardation. Throughout her life I have made every effort to incorporate her choices into daily activities. However, choice has always been difficult for her. She takes a long time choosing between two items, whether clothing, food or activities. And when she appears to have decided, she often changes her mind. I have done my best to give her as many choices as possible, with the understanding that her first choice was "it" until next time.

When it came time to consider Leslie moving away from home as her brothers had, I had to explain to her that while that might be an option for her sometime in the future, she needed to learn some skills before that could be considered With the help of her case manager we started a group home for her, and in the three and one-half years Leslie has lived there she has made more progress than I ever could have dreamed. She has mastered self-care skills that she never would have at home - and taken pride in that mastery. She has learned to do household chores such as washing her own clothes and cleaning her bathroom - because she now lives in a cooperative setting, not in her parent's home. Without a particularly rigorous diet and with some judicious exercise that others around her were also doing, she has lost over 80 pounds and now loves to shop for "thin" clothes. Leslie has also been taught and now practices some valuable self-regulatory skills; when she feels herself becoming agitated or annoyed, she often asks if she can go relax for awhile or responds to that suggestion from a staff person.

There is still a ways to go to before Leslie will be able to take full personal control of her residence, job, and other activities. That time may never come in its entirety. But she has been given the opportunity to learn what choices she can make and to see what choices are out there. I am extremely proud of the progress she has made. And I know how important it is for her to continue to learn to make her own choices for that time when I will no longer be here to be involved in her life.

By Barbara Polister, Project Coordinator with the Institute on Community Integration, University of Minnesota, Minneapolis.

What About *Environment*?

by Brian Abery and John Smith

When most of us think about self-determination, we focus on the individual. The control a person exercises over their life is typically perceived to be a result of internal factors including their skills, attitudes/beliefs, and knowledge. The self-determination equation, however, is not that simple. The immediate environments within which we live, the linkages between these settings, events that occur within environments in which we do not directly participate, and the institutional/ideological patterns of society all play a major role in self-determination.

The immediate environments in which we develop and live - the family, school and work, and the peer group - are what often comes to mind when the environmental determinants of self-determination are discussed. The importance of these settings as they are related to the development of the self-determination skills of individuals with developmental disabilities is critical. It is important to remember, however, that skills are of little value if persons in authority within these immediate settings do not provide opportunities for individuals to exercise personal control.

An individual's interactions with others do not occur in isolation. Behaviors and skills learned in one environment need to be supported and practiced in others if generalization is to occur. The lack of linkages that exist between families and schools, schools and social service agencies, employment sites and other human service agencies often result in a lack of collaboration that has a decidedly negative effect upon self-determination. The authors have experienced situations in which professionals within one environment are encouraging enhanced personal control on the part of persons with developmental disabilities while those in other settings are actively discouraging it. Until family members, educators, and other human service professionals all learn to collaborate in supporting the right of individuals with developmental disabilities to "take charge" of their own lives, enhanced self-determination is likely to remain an unfulfilled promise.

It is not only those interactions that take place within environments in which persons with developmental disabilities directly participate that have an effect upon self-determination; one must also consider the impact of the external contexts in which these settings are imbedded. The quality and type of training to which teachers, work supervisors, and residential staff have been exposed, and decisions made by school boards as whether students with developmental disabilities will be taught choice-making and personal advocacy skills and given opportunities to assume some degree of personal control over their education will all have an impact upon self-determination. Unfortunately, as of this date, few educational or human service professionals receive preservice or inservice instruction in methods to facilitate the assumption of personal control. In fact, the degree of "structure" in educational, residential, and work settings advocated by most trainers removes many opportunities for persons with disabilities to exert control over their lives.

In order to fully understand the changes that will need to occur if individuals with developmental disabilities are to have "equal opportunities" for self-determination, one also needs to examine the overarching institutional and ideological patterns of the culture. Stereotypes about persons with disabilities and the resulting discrimination against such individuals, for example, are based upon the manner in which members of western society perceive persons who are "different" from themselves. The common belief that persons with developmental disabilities are unable to know "what they want out of life," and therefore must have others make decisions for them is rooted in the way in which our society perceives and devalues such individuals and the resulting "deficit-based" service-system that has been developed to provide "support" (i.e., control).

The manner in which society treats persons with disabilities has changed significantly over the last several decades. If individuals with developmental disabilities are to function as self-determined adults, however, further change is necessary. Legislation does not guarantee changes in society's perceptions, as has clearly been experienced by women; persons of color; gay, lesbian and bisexual individuals; and persons with disabilities. Many attitudinal barriers related to disabilities still exist and remain to be addressed. Against this societal background, it is easy to understand why many family members and professionals are reluctant to give up the control they currently exercise over persons with developmental disabilities.

Exercising personal control over where and with whom one will live, a career/employment path, and one's social relationships is something most adults take for granted. Unfortunately, this is often not the case for persons with developmental disabilities. If families, professionals, and others are serious about enhancing the self-determination of persons with developmental disabilities, the focus of education and intervention efforts will have to be broadened to include not only persons with developmental disabilities themselves, but those persons and systems that comprise the environments in which they live.

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I was doing at all; college was completely different from high school. I knew about having more freedom, but I didn't realize that additional responsibility went hand-in-hand with that freedom.

The biggest of my new responsibilities was learning how to handle the local paratransit system. I assumed that rides were handed to you on a silver platter whenever you needed them. I learned the hard way that I was wrong. During my first quarter of college I missed 10 of the first 12 of one of my classes because my rides were delayed, late, or did not arrive at all. I didn't realize that as a consumer I had rights. When I was informed of my rights by the paratransit staff, I began filing formal complaints whenever there was a violation by the carrier. By December of 1992, after filing six formal complaints, I made the carrier realize that I meant business and they began respecting me as a consumer.

My first year of college also brought along with it my first experience with hiring a PCA. In school, I need a PCA for note-taking, book manipulation, and to assist me with other personal needs. In high school, the school district handled hiring of PCAs. Once I left high school, it was up to me. I only spoke to one person from MCIL about hiring a PCA before I did it. I didn't know much about hiring and it didn't work out very well. The first woman I hired was a nice person with good credentials, but she hated the school scene and everything to do with it. She jokingly suggested that I skip class and not do my homework. Over time, this became a little annoying, but I wasn't quite sure how to tell her to stop. One of the reasons I didn't know how to stop her was because I was afraid that if I spoke my mind, she would quit. So I muddled through. She quit during spring quarter; it wasn't until then that I realized that there is more than one PCA in the world. I transferred to a much more reputable agency. This agency seemed to care more about their clients than the prior one did. They trained their PCAs better. The second time around, I knew what questions to ask and what qualities to look for. I learned something else as well; each individual has unique needs, and I learned how to get my individual needs met.

Currently I attend a local community college. The college has an Access Director who is designated to handle any extra needs (special equipment, etc.) of the students with disabilities. At the beginning of my first fall quarter, the college had just hired a new director who knew little about the college and it's services. This was frightening for me because I was in a fairly new setting and I knew more about the situation than the person who was supposed to support me. I was a new student at college with no one to help with my special needs. My PCA, some staff members of the college, and I figured out how to get through those first few weeks. I successfully acclimated to college life without much assistance from the director. Now I rarely call on him for assistance.

My future plans include attending a four-year college where I will major in psychology. After completing a graduate degree in education, I hope to be an accessibility consultant. Overall, I think that I can say that experience is a better teacher than any classroom curriculum. In making the transition from high school to college, I learned to be my own self-advocate and get what I need.

By Holly Meister, who lives and attends college in suburban Minneapolis.

Resources on Self-Determination

- **A Guide to Enhancing the Self-Determination of Transition-Age Youth with Disabilities.** (1994). A skill-building and family education/support curriculum. By B. Abery, A. Eggebeen, E. Rudrud, K. Ardnt, and L. Tetu. Published by and available from the Institute on Community Integration, University of Minnesota, 109 Pattee Hall, 150 Pillsbury Dr. SE, Minneapolis, MN 55455 • (612) 624-4512.
- **Self-Advocacy: Four Easy Pieces.** (1993). A videotape and and trainer's guide for use in teaching people to become self-advocates. Produced by and available from Advocating Change Together, 1821 University Ave., #S-363, St. Paul, MN 55104 • (612) 641-0297.
- **Living Your Own Life.** (1994). A book for adolescents, written by adolescents with chronic illness or disability. Published by and available from PACER, 4826 Chicago Ave. S., Minneapolis, MN 55417 • (612) 826-2966.
- **Self-Determination and the Education of Students with Mental Retardation.** (1992). By M. Wehmeyer. In Education and Training in Mental Retardation, 27, pp 302-314.
- **Self-Determination Revisited: Going Beyond Expectations.** (1991). By M. Ward. In Transition Summary, 7, National Information Center for Handicapped Children and Youth, Washington, DC, pp 3-5, 12.
- **A Conceptual Framework for Enhancing Self-Determination.** (1994). By B. Abery. In Challenges for a Service System in Transition: Ensuring Quality Community Experiences for Persons with Developmental Disabilities. Editors: M. Hayden and B. Abery. Published by Paul H. Brookes, Baltimore.

Family, continued from page 1

new job "experience" across town starting at 1:00. The criteria for success established by his school was that his work had to approach 95% of the quantity and quality of a person without mental retardation. He failed...week after week. On the fifth week he announced, "I keep telling you, this is the best that I can do. If it isn't good enough I'm not coming anymore."

I am always in awe of Christian's tenacity. I remember all the days and nights in hospitals, feeling helpless to free him from painful, restrictive treatments and procedures. I remember being unable to speak up when he was treated as if he were invisible by doctors and teachers, simply because he was a child...and "retarded." I remember the past 18 years of special education and IEP's, and feeling incompetent and alone at the table at which professionals typically used acronyms and languages I didn't understand or agree with. The words "severe", "profound", "can't", "flat scale" and "inappropriate" will always send shivers up my spine. I remember when the neighbor kids started the name calling: "fag", "retard", and "cripple".

It was difficult for me to move past the pity and protection. However, my basic values dictated that I raise all of my four children in a home that valued their voices and encouraged discussions about their thoughts and feelings. Also, before I ever had children I knew that the first priority to teach them was compassion. I didn't know anything about self-determination, but Christian was able to risk saying the wrong thing or making a mistake because he knew no matter what happened, home was a place where he was valued, accepted, and loved.

By the time Christian was seven he was frustrated and angry about his disability. My first reaction was to protect him from experiences that would cause pain or frustration. I felt that was part of my job description as a parent. By the time he was 10 I knew I was not doing him a favor. I began to question if I was responding out of pity or love. I quit feeling sorry for Christian. We regularly discussed how he had to live with himself and learn to understand what seizures were and what mental retardation meant for him. At the same time the family, including his brother and sisters, supported and went to bat for him when attitudes and programs he experienced demeaned and devalued him.

Self-advocacy and self-determination begin with advocacy. Christian observed his dad, myself, and his siblings all standing up for his rights. Not only did that allow him to learn behaviors, but he knew he was worth the fight. For example, it was wrong for a teacher to set up a classroom reward system with criteria that never allowed success for Christian. When he displayed anger, he was called psychotic; we went through due process. It was also wrong for hospital staff to continue to insist on further sedatives when they had already administered a high enough dose to put a 200 pound man out cold; we left AMA (Against Medical Advice).

As an advocate I could be in charge and direct the course of action and be the decision maker. The real challenge for me was when adolescence arrived. All the skills I'd hoped Christian would have, appeared. I was disjointed, fearful, confused, and struggled with his "non-compliant, inappropriate and aggressive" behaviors. Oops! The change meant I had to look at my values again in order to step back and support Christian in decisions I didn't always agree with and often thought were dangerous. I needed to believe that he would make decisions that would keep him safe, physically and emotionally. In the beginning I also needed to believe that "the world" would view his contributions as important. I struggled with my perceptions of mental retardation being at the bottom of the disability list and the possibility that he would have no caring person in his adult life. Not all the choices that Christian has made have been safe, physically or emotionally, but they have been his choices.

For instance, Christian's first major purchase with his SSI money was a chainsaw. In another instance, Christian, who cannot drive a car, bused around the city, found a 19 foot boat to purchase, and now is looking for a "friend" (paid or unpaid) to get the boat to water. Two days ago he was at the corner waving cars down and offering to pay $100 for a drive to a lake. He recently announced that there must not be any available women who could possibly like him so he was going to pay for that service also. I have learned to spend a great deal of time taking hot baths or putting invisible masking tape over my mouth.

Self-determination requires that a person have rich and abundant experiences. In order for growth in confidence and the ability to make choices a person must have successful and unsuccessful experiences. Christian has used that chainsaw and other power tools to help clear a wooded area and build a deck. He is currently enrolled in a technical college in the chef program, using meat cleavers and very sharp knives; a few supportive people in the decision-making role decided not to be afraid that he would have a seizure and get hurt. When he goes to the lake with the family, Christian drives that 19 foot boat and skillfully docks it because his dad and I decided that to risk paying for a dent in another boat was worth building Christian's confidence. Christian can say no to drugs, alcohol, and abuse because his siblings have included him in their typical teen parties and he's had the opportunity to say no.

Christian may still be vulnerable, and may still get frustrated by his mistakes and angry at attitudes that isolate him. But, he has a strong determination to know, understand, and like himself...and he knows that he is worth it.

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