

## **Self-Determination and Self-Advocacy: Shifting the Power**

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### **A Brief History**

In order to understand the meaning of words such as self-determination and self-advocacy, we must first understand their history. For many years, people with disabilities lived in the shadow of others. They were abused, mistreated, and virtually ignored. In the past century and a half, services for people with developmental disabilities have gone through many phases of good-faith effort, each with notable intentions. Beginning around 1848, we developed special schools and training programs based on the belief that we could teach people with disabilities better if they were separated from the "normal" population. Those schools were set up outside of our local communities and became known as institutions (Wolfensberger, 1969).

After more than 100 years, the focus shifted toward the ideal known as normalization, which exposed institutions as facilities that strip individuals of their humanity and connection with society, and established the community system as the vision. In the 1980s the drive for inclusion surfaced, criticizing "home-like" and "job-like" simulated programs as enforcing segregation and failing to lead to community leadership. Around the same time, advocates began concentrating on each person's life as an individual, an approach later referred to as person-centered planning.

A notion that became strong in the United States during this period was self-advocacy. Self-advocacy focuses on the ability to stand up for oneself and to help other people with disabilities stand up for themselves by speaking up, speaking out, and speaking loud. It means having the opportunity to know your rights and responsibilities, to stand up for them, and to make choices about your own life. It means getting a Big Mac if you want, instead of being "encouraged" or forced to eat a salad instead. Self-advocacy means helping people understand that we are all "able" and empowering people to take control over their own lives to make decisions and take the consequences. Self-advocacy is a process a way of life that is an ongoing learning experience for everyone involved. It means taking risks and going after your dreams. It means making mistakes and learning from them. Self-advocacy is a revolution for change, to enable people with and without disabilities to live in harmony. Self-advocacy is founded on the belief that together, we can create the spark to light the fire of a better life for all of us.

In the 1990s we wrapped up these ideas into a philosophy called self-determination. The self-determination movement evolved as a result of social movements involving disability rights and self-advocacy. In essence, self-determination is a call for shifting power from the system to the individual, allowing people to choose how they live and to be supported in ways that facilitate their preferences. Martin and Marshall described self-determined individuals as knowing

how to choose--they know what they want and how to get it. From an awareness of

personal needs, self-determined individuals choose goals, then doggedly pursue them. This involves asserting an individual's presence, making his or her needs known, evaluating progress toward meeting goals, adjusting performance and creating unique approaches to solve problems. (1995, p. 147)

Self-determination focuses on reforming systems to provide greater opportunities for choice and self-direction and on providing people with disabilities with skills and information so they can express self-determination in their own lives. Further, it focuses on four principals:

1. Freedom--the ability for individuals, with freely chosen family and friends, to dream and plan a life with necessary support rather than to purchase a preplanned program from the system;
2. Authority--the ability for a person with a disability, with a social or support network if necessary, to control a certain sum of dollars in order to purchase supports;
3. Support--the arranging of resources and personnel, both formal and informal, that will assist an individual in everyday living; and
4. Responsibility--the acceptance of a valued role in a person's community through competitive employment, organizational affiliations, spiritual development, and general caring for others in the community, as well as accountability for spending public dollars in ways that are life-enhancing.

## **The Self-Determination Movement**

Several models of self-determination are being implemented in the United States. In different locations, the idea of self-determination is being implemented in a different way. There is no one perfect outline or approach, because self-determination is the simultaneous combination of many components, such as self-awareness, independence, education, choice, reflection, evaluation, self-advocacy, and community-based activities.

The most common approach to self-determination has been the creation of pilot sites and experimental project initiatives to explore changes in the service delivery system. One factor that has helped shape the self-determination agenda in the United States has been the grants distributed by the Robert Wood Johnson Foundation. This has involved a \$5 million program designed to help states change their service systems in ways that promote self-determination. In addition, grants have been made to a variety of organizations (including People First and The Arc) to enable them to support and assist with these changes. The Monadnock Self-Determination Project in New Hampshire, which was awarded funding in 1993, was one of the first attempts to change how the service system operates. Anita Yuskas, PhD, James Conroy, PhD, and Martin Elks, PhD, from the Center for Outcome Analysis in Ardmore, Pennsylvania, were hired to perform an independent evaluation of the project's impact on quality of life among the project participants and to study the systematic, organizational, and economic implications of the project. According to their findings,

essentially, the process started with a small group of committed leaders who created a core set of principles for which they elicited support. Once support was engendered, there was an emphasis on collaboration and group problem solving to continue the initiative. This maintained uniformity of values among the participants, which was

essential as role and system boundaries changed. Three additional changes involved the struggle to shift from a reliance on money to a reliance on community, the creation of a risk pool for service providers willing and committed to make changes according to the defined principles, and a transformation in the management of money, away from programs to individualized budgets. (Yuskauskas, Conroy, & Elks, 1997)

As Robert Wood Johnson initiatives expand across the United States, the main concern is how to create a system that simultaneously fosters political or collective self-determination and supports individual preferences.

A second major initiative, implemented between 1990 and 1996, was undertaken by the U.S. Department of Education through the Office of Special Education's self-determination funding model demonstrations and assessment development projects to promote self-determination for youth with disabilities. These projects focused on various aspects of self-determination, including teaching person-centered strategies for achieving self-determination, curricula pertinent to unique issues of self-determination (e.g., leadership through augmented communication), adaptation of "People First" strategies to the self-determination philosophy, and ethics and self-management skill training (Ward & Kohler, 1996).

Analysis of project activities by Ward and Kohler (1996) indicated that projects funded by the Office of Special Education developed curricula to teach students to evaluate their skills, recognize their limits, set goals, identify options, accept responsibility, communicate their preferences and needs, and monitor and evaluate their progress. The activities taught decision making, goal setting, self-awareness, and self-advocacy. To teach these skills, teachers, mentors, and parents modeled self-determined behavior, involved students in role play and simulated situations, developed student portfolios, and used videotape to instruct and provide feedback. Furthermore, projects conducted numerous activities in community settings such as business and industrial sites, the public service sector, postsecondary education and training facilities, residential environments, and community art centers. To increase the capacity of others to recognize and promote self-determination, many projects trained teachers, parents, and other significant adults in students' lives. Finally, projects created opportunities for students to exercise their newly developed skills and in some cases formally positioned students as leaders in the Individualized Education Program process (Ward & Kohler, pp.285-286).

Analysis of projects that included these activities showed that students had an increase in behaviors and skills related to self-determination (Ward & Kohler, 1996). As a result of these initiatives, the self-determination movement has extended its energy to include the community as a whole as a mechanism for changing how people with disabilities are treated.

## **The Self-Advocacy Movement**

The evolution of self-advocacy has been a striking feature of the movement toward self-determination. State and local organizations have become more organized and influential in determining the status of the service delivery system. Self-determination is a central theme for self-advocates, and many local groups have begun gathering basic information about the self-

determination movement. These groups have an increasingly important role to play in shaping the services and support offered to people with disabilities.

Unfortunately, self-advocates still face many challenges. The first obstacle to overcome is a lack of experience. Although self-advocacy has been in existence in the United States since the early 1970s, individuals with disabilities were not fully included in the self-advocacy "wave" until the 1990s. Only recently have self-advocates been asked to participate as fully contributing members of local, state, and national boards focusing on issues involving people with disabilities. However, many organizations appear to have stopped at that point. It is important that they provide appropriate training and support to empower self-advocates to have more than a token role.

The second obstacle is a continued lack of support by the community as a whole. There are three aspects of today's society that have contributed to this lack of support. The first aspect is fear. Despite wonderful efforts to disseminate information about the valued roles that people with disabilities can play, the general public is fearful of people who are different and sometimes even believes them to be dangerous. The second aspect of society that has created a lack of support is the question of liability. People who provide guidance and assume responsibility for the actions of a person with a disability are sometimes unsure of where to draw the line between a self-determined decision by the person with a disability and health or safety concerns of family members and staff, which usually means that all options are not thoroughly explored.

The third aspect is the matter of financial control. As trends change, people in authority are beginning to give monetary control back to the individual. Concerns have been raised about giving money to a person who does not have experience in handling it. In order to get past this, we must provide opportunities for people with disabilities to learn important money management and budgeting skills. The third obstacle facing self-advocacy is that many people with disabilities lack leadership skills. Understandably, "leadership" has become a catchphrase in the self-advocacy movement: People with disabilities want to be in decision making positions. They are tired of being mere stakeholders; they want to be the executive officers. However, most states are just beginning to offer training to increase self-advocacy and leadership skills. In order to be effective, these training sessions should have components similar to those employed in the projects of the Office of Special Education initiative.

These challenges have not stopped the movement; they have just redirected its emphasis. In 1991, a national self-advocacy group surfaced: Self Advocates Becoming Empowered (SABE). SABE received a 3 year grant from the Administration of Developmental Disabilities in October 1999. The grant is for a project of national significance called Project Leadership. SABE will work with the National Parents Network, the National Program Office on Self Determination, and the Center on Innovations of Community Options on this grant. Project Leadership's goals include developing leadership training kits and curricula, training self-advocates and parents throughout the 3 year cycle, and developing a national network of self-advocates and parents.

## **Emerging Role for Professionals**

Over the years, the role of disability professionals has changed drastically. There have been three

major phases. For years professionals served as the decision makers for people with disabilities. They decided what they would eat, what they would wear, and when they would go from room to room. With the rise of self-advocacy, professionals became "advisors" for people with disabilities. During this phase, the professional has had a responsibility to oversee the person with a disability and encourage him or her to make the "right" decision. As self-determination becomes the center of discussion, power is shifting over to people with disabilities, which puts the professional in the role of "consultant." "With this shift, people with disabilities are now the responsible party. The difference between the roles of advisor and consultant is that the consultant gives people with disabilities a choice. They rely on the professional to provide education, training, and assistance so they can make informed decisions. No longer must they bow to the assumptions of the "decision maker" or the influential opinions of the advisor. It is important that professionals pay attention to their own actions and know when to step back, because the very nature of self-advocacy and self-determination is to give people with disabilities a chance to be self-reliant.

## **Community Involvement**

This nation has created a system of "community" services that frequently fosters isolation from community. We are painfully aware that, though well intended, this separation causes people to be perceived as "different." Their quality of life suffers and their basic human rights may be jeopardized (Nerney, Crowley, & Kappel). How can we change this?

The recurrent theme in normalization, person-centered planning, inclusion, and self-determination has been the focus on "normal" community involvement and on integration. However, the majority of these attempts have been made through a program to stimulate the natural system of creating relationships with other people in the community. Surprisingly, little effort has been made to educate the community as a whole. As a result, many people with developmental disabilities have not gained the knowledge they need in order to be fully integrated into the community. In many cases, independence in decision making has equated to isolation from community life. Some advocates have attempted to ease the journey into community life through support by a designated Circle of Friends (Amado, 1993). This has been successful in initiating connections with the community. However, this approach does not always offer the information necessary to fully access community life beyond the circle. In order to fully access community life, we must start at the heart of the community, working from the inside out, with a focus on overcoming differences and bringing people of different backgrounds together.

Research by Mary O'Connell (1990) of the Community Development Program at Northwestern's Institute for Policy Research in Evanston, Illinois, has shown that community building can be an efficient, inexpensive way to help people with disabilities get integrated into community life. O'Connell's community building project in a Chicago neighborhood linked nondisabled community members with people with disabilities in an attempt to help people with disabilities be more active participants in their own community. Many of the people with disabilities encountered positive changes in their lives and increased their level of community involvement. According to O'Connell, an essential component of this framework should be knowledge and training on how to access the community independently. This type of work "must not be an extension of the formal system but be located in the civic sector ... the place where people come together as citizens" (1990, p. 41).

## **The Road to Self-Reliance**

Throughout the United States there is an attempt to educate and train people with and without disabilities about the history and principles of and tools involved in self-determination and self-advocacy. Many groups have set up grassroots projects offering training and obtained funding through grants. Training sessions are being held through local self-advocacy meetings, workshops, and conference presentations. Some organizations are offering training in basic self-advocacy skills (e.g., communication, assertiveness, leadership, and teamwork) as a route toward self-determined behavior. Many of these training sessions are being engineered through Partners in Policymaking, Self-Determination Leadership Networks, and grant-funded self-advocacy groups and projects. One of the initiatives currently being funded in North Carolina is Steps Toward Independence and Responsibility (STIR). STIR is a project team at the Center for Development and Learning at the University of North Carolina at Chapel Hill. It is run for and by people with developmental and other disabilities. The project serves to support self-determination and self-advocacy through coordination of training, technical assistance, and support of new self-advocacy groups throughout North Carolina.

STIR workshops build knowledge and help create leadership options for people with disabilities. STIR offers training directly to self-advocates, parents, family members, friends, and professionals, using a variety of approaches including slide presentations, small group discussions, video, and hands on fun activities designed to teach about how to be a leader. All proceeds from training will be used to support the work of team members in providing future training and education for people with developmental disabilities.

Due to the growing need for and desire of people with disabilities to learn about self-advocacy and leadership, STIR has created Pathways to Community Leadership. This training program promotes self-determination of people with and without disabilities by providing them with knowledge, skills, mentoring, and peer support. Major program areas include self-awareness, knowledge of the existing community (local, area, state), general advocacy skills, leadership, and teamwork. The key to providing this knowledge is making connections with individuals at every level of the local community, ranging from family and friends to small businesses, churches, associations, libraries, and clubs.

In October 2000, the University of North Carolina at Chapel Hill received a grant from the U.S. Administration on Developmental Disabilities for a collaborative project involving STIR, the Association of Self-Advocates of North Carolina, and the North Carolina Self-Determination Leadership Network. The new project, titled Shifting the Power, will provide training and technical assistance on self-advocacy, self-determination, and leadership to self-advocates. The Pathways to Community Leadership curriculum, developed by STIR, will be the primary resource used in the project. States interested in this training opportunity will be required to provide evidence of need for the training and agree to provide the training to people with developmental disabilities who do not typically have access to leadership training due to language barriers, cultural differences, or restricted living environments (such as institutions or nursing homes).

## **ABOUT THE AUTHOR**

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## REFERENCES

- Amado, A. N. (1993). *Friendships and community connections between people with and without developmental disabilities*. Baltimore: Brookes.
- Martin, J. E., & Marshall, L. H. (1995). ChoiceMaker: A comprehensive self-determination transition program. *Intervention in School and Clinic, 30*, 147-156.
- Nerney, T., Crowley, R., & Kappel, B. (date unknown). *An affirmation of community, a revolution of vision and goals: Creating a community to support all people including those with disabilities*. Retrieved October 15, 2000, on the World Wide Web: [www.unh.edu/rwj/library/afc.htm#preface](http://www.unh.edu/rwj/library/afc.htm#preface)
- O'Connell, M. (1990). *Community building in Logan Square: How a community grew stronger with the contributions of people with disabilities*. Chicago: Community Building in Logan Square Center for Urban Affairs and Policy Research, Northwestern University.
- Ward, M. J., & Kohler, P. D. (1996). Promoting self-determination for individuals with disabilities: Content and process. In L. E. Powers, G. H. S. Singer, & J. Sowers (Eds.), *On the road to autonomy: Promoting self-competence in children and youth with disabilities* (pp. 275-290). Baltimore: Brookes.
- Wolfensberger, W. (1969). The origin and nature of our institutional models. In R. B. Kugel & W. Wolfensberger (Eds.), *Changing patterns in residential services for the mentally retarded* (pp. 59-171b). Washington, DC: President's Committee on Mental Retardation.
- Yuskauskas, A., Conroy, J., & Elks, M. (1997). *Live free or die: A qualitative analysis of systems*. Ardmore, PA: Center for Outcome Analysis.