# Advocacy: The Power Within

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## Abstract

*In recent years, individuals who have severe disabilities have begun to self-advocate, thus challenging the stereotype that individuals with severe disabilities cannot speak for or legally represent themselves. By confronting discriminatory policies and regulations directly, people with severe disabilities construct roles for themselves that demonstrate self-determination, advocacy, and empowerment. This article addresses: the importance of advocacy for individuals who have severe disabilities, existing barriers faced by advocates and self-advocates, and how these barriers can be overcome by persons with disabilities through support from vocational special needs programs. The article also discusses the positive impact of vocational special needs on individual and group advocacy, particularly self-advocacy for persons with severe disabilities.*

## Background

The concept of equal rights and opportunities for persons who have disabilities is relatively new. In the past, advocates have invoked the power of the government to obtain their civil rights. Individuals who have severe disabilities are the most recent disability group to demand their rights. They ask for an end to discrimination and for increased access to education and employment. Many express their needs through the politically and socially empowering forum of advocacy.

Advocacy has been traditionally defined as speaking for, or on the behalf of, oneself or another person (McDonnell, Hardman, McDonnel, & Kiefer-O'Donnel, 1995). Advocacy occurs either through the work of organizations or of individuals. These organizations may politically lobby for appropriate support services for persons who have disabilities. Advocacy groups also may positively influence federal and state policies that directly affect the lives of persons who have disabilities such as the Vocational Rehabilitation Act (1973) or the more recent Carl D. Perkins Vocational and Applied Technology Education Act. Individual advocates often refer people to needed programs and services (Rios & Comstock-Galagan, 1994) and help those with disabilities advocate for their own legal and social service rights. As these advocates inform the public about the rights of people who have disabilities, attitudes are changed.

In recent years, individuals who have severe disabilities have begun to self-advocate, thus challenging the stereotype that they cannot speak for or represent themselves. Along with this self-advocacy has come empowerment, "the process by which people gain more control over the decisions that affect their own lives" (Balcazar, Seekings, Fawcett, & Hopkins, 1990). Empowerment is one of the key components of advocacy, and is a pivotal feature in assessing an individual's quality of life (Wolfe, Ofiesh, & Boone, 1996). Empowerment assumes that individuals are already competent and learn new competencies in context by participating in life experiences. By directly confronting discriminatory policies and regulations, people who have severe disabilities construct new roles for themselves that demonstrate empowerment, self-determination, and advocacy (Brooks, 1991).

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The advocacy movement is important to vocational field because Vocational Special Needs (VSN) personnel can train persons who have disabilities to advocate for themselves in regard to employment and job training (Lynch & Reimer, 1997; Brookes, 1991). Advocacy thus helps people who have disabilities develop and utilize neces-

sary skills in job settings, which can lead to a reduction of underemployment of people who have disabilities (Hardman, Drew, & Egan, 1996).

## Types of Advocacy

"Advocacy has brought forth a well-organized, internationally connected movement that provides a growing voice to what was, until the recent past, a universally rejected minority among a nation's minorities" (Dybwad & Bersani, 1996). As persons who have disabilities have obtained increased civil rights, advocacy programs have flourished with new strength and enthusiasm.

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Here we discuss three categories of advocacy that have been primarily used by people concerned with the rights of people who have disabilities: (a) individual advocacy, (b) group advocacy, and (c) self-advocacy.

### Individual Advocacy

Individual advocates work to increase awareness and improve current policies and practices that affect persons who have disabilities. Issues important to individual advocates include education, transportation, employment, medical services, or entitlement programs. Experts (Lynch & Reimer, 1997; Salembier & Furney, 1995) have stated that individual advocacy for individuals who have disabilities is important in employment settings. With the passage of the Americans with Disabilities Act in 1990, people who have disabilities have additional legal means to seek an end to the long-standing

discriminatory practices in employment and job training. Individual advocates can be a part of an informal system such as parents, teachers, friends, or part of a formal support system such as the health or education system (McDonnell et al., 1995). It is estimated that 80% of the care and support given to people who have disabilities comes from informal sources (Rhoades, Browning, & Thorin, 1986) and that, in most cases, individual advocates are part of these informal networks.

Individuals who advocate for persons who have disabilities often "inherit" the position. For example, a child who has a disability may be born to a parent or an individual may have a friend who develops a disability creating a relationship in which individual advocacy becomes important and develops. When this situation occurs, the family or friend often finds a new passion and begins advocating for this person. Other people choose to be advocates because they feel they have something to offer people who have severe disabilities. Along with this advocacy, an individual may begin advocating for others who have disabilities. Individuals who advocate for persons who have disabilities often reflect this role by focusing on day-to-day needs such as educational placement, accessibility to employment, or immediate medical needs.

### Challenges of Individual Advocacy

There are some specific challenges for individual advocates. First, the individual advocate can feel isolated from the rest of society and feel as if he or she is fighting a solitary battle. Secondly, individual advocates can be limited in what can be accomplished as they tend to focus only upon the specific type of disability that impacts the individual (e.g.

cerebral palsy). Finally, the individual advocate can have a limited impact on state or federal changes for persons who have disabilities, as individual lobbying usually does not have the same strength as does group lobbying. Despite these specific challenges, individual advocates are a strong voice for persons who have disabilities and they must continue their mission. The constituency of individual advocates maintain the personal push for the rights of persons who have disabilities.

### Benefits of Individual Advocacy

Persons who have disabilities greatly benefit from the efforts of individual advocates. Individual advocates often speak out on behalf of people who have severe disabilities; a group that sometimes cannot represent their own advocacy needs. Also, individual advocates persist in their efforts regardless of federal challenges or political changes because of their personal commitment. People who have severe disabilities are often reduced to a diagnosis or a label for administrative expedience (Blatt, 1994) instead of being treated as people first.

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This is a serious problem as a disability is neither a disease nor a condition that possesses predictable characteristics (Blatt, 1994; Kennedy, 1994). Individual advocates highlight the human aspect to the disability rights movement.

A unique group of individual advocates are parents who have children with disabilities. Parents assume the role of advocate the moment their child is born

(Morningstar, Turnbull, & Turnbull, 1995; Blossom-Weimer, Cappotelli, & DiCamillo, 1994; Dane, 1985). Parents have expertise and knowledge about their child that is unparalleled by any professional group (Dane, 1985) and, thus, are often the strongest advocates for their child. Parents often find that their most valuable resource is other parents of children with disabilities. They can share ideas, information, and emotional support with someone who has had similar experiences (Nisbet, 1992).

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Career and technology education in the public schools has been a supporter of inclusion for students with mild disabilities for over twenty years. Just recently has the trend been to include students who have severe disabilities in general education. By offering students who have mild disabilities the opportunity to participate in general education courses, vocational teachers and administrators established a trend of individual advocacy by supporting, encouraging, and providing classes for all public school students. This same trend is beginning to be implemented with public school students who have more severe disabilities (Fabian, Lent, & Willis, 1998).

### Group Advocacy

Groups are usually more formal disability advocacy vehicles than individuals. Group advocates, due to size, financial resources, and people can impact policymakers about issues related to employment and job training for people who have severe disabilities (Hazelkorn & Lombard, 1994). Disability organizations have successfully lobbied policy makers to improve social services for people who have severe disabilities. They also serve as important contact points for information and assistance to families, and are influential in creating awareness of the needs of people who have severe disabilities (McDonnell et al., 1995). Group advocacy exists because there is a common goal among the advocates. A common goal of advocacy groups for persons who have disabilities is to obtain the appropriate services and the legal constitutional rights that all people deserve (Novotny, 1990).

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Advocacy groups first formed among individuals who had similar disabling conditions such as blindness or mental retardation. As early as the 1940s, a parent advocacy group was formed to address the needs of children who had cerebral palsy and mental retardation (Dane, 1985). Availability of educational programs for students who had disabilities was limited and parents became increasingly concerned. From this concern, stemmed the development of more advocacy groups. Examples of formal advocacy organizations, supported by both parents and professionals, include The Arc (formerly called The Association for Retarded Citizens) and the Council for Exceptional Children (CEC).

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People who have visual impairments, people who have orthopedic impairments, and people who have epilepsy may not perceive themselves as occupying common ground (Scotch, 1988). Thus, most advocacy groups are usually organized around specific types of disabilities, severity, age of onset, and prognosis. In the 1980s, advocacy groups began to see the merits of coalition, recognizing that they could accomplish more in the political system if they joined together. By the 1970s, several organizations (e.g. TASH – formerly known as The Association for Persons with Severe Handicaps) had been formed that crossed disability lines and encompassed individuals with a wide range of physical and mental disabilities.

Vocational education has been a leader in the inclusion of students who have mild to moderate disabilities into career and technology education classes. Career and technology educators and administrators have been some of the strongest supporters of job training and education of students with disabilities (Lynch & Reimer, 1997. This leadership is being implemented now with students who have more severe disabilities, both cognitively and physically (Woody, 1993; Novotny, 1990).

### Challenges of Group Advocacy

Advocacy groups have traveled a somewhat rocky road because of their commitment to their original constituents. In addition, disability groups often compete

with each other for resources and prestige even though their goals – supporting independence, full participation, and empowerment – are the same.

In addition, state and national advocacy groups are directly affected by the political party in power. There is a concern that persons who have disabilities will be denied employment and educational services because of attempts to reduce the budget (Advocacy in Action, 1995). Advocacy groups often have strong lobbies. Lobby reforms would seriously threaten participatory democracy in our nation and prevent people with disabilities from accessing information through nonprofit groups (Wheeler, 1995). Thus, while group advocacy is powerful, it can be challenged and hurt by legislative powers.

### Benefits of Group Advocacy

Group advocacy benefits individuals who have severe disabilities by: (1) providing informal support systems within the community; (2) improving self-identity; (3) providing an opportunity for meaningful friendships; (4) recognizing that the stigma and prejudices that they experience are a result of societal ignorance; and, (5) banding together people to demonstrate strength and to help bring about change (Rhoades et al., 1986). Again, group advocacy is particularly effective because there is "strength in numbers."

Advocacy groups have aggressively spoken out on behalf of legislative support for persons who have disabilities and are a key reason for the passage of legislation such as the Americans with Disabilities Act (Huber, 1995; West et al., 1993; Woody 1993). Furthermore, advocacy groups along with career and technology educators help the public realize that educat-

ing, working with, and hiring persons who have disabilities is beneficial for all (Porter, 1995).

Groups who do not have disabilities, such as racial and ethnic minorities, usually share a geographical community, workplace, or religious association. These groups develop their own subcultures based on their collective history or social position. This has not been true, however, for people who have severe disabilities. Today, people who have disabilities are the nation's largest minority, and the only minority group that <u>any</u> person may join at any given time (Foster, 1996). Group support of advocacy has increased and improved opportunities for this largest minority group, despite the many challenges present.

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With the passage of vocational legislation in the 1970s and with revisions to current legislation underway, vocational education was and continues to be a primary force in group advocacy for people with disabilities. Federal legislation related to disability issues, such as The Americans with Disabilities Act (1990), was directly influenced by early vocational legislation. Because of efforts by vocational education, group advocacy for people who have disabilities has grown and flourished.

### Self-Advocacy

"Self Advocacy," in which people who have disabilities advocate for themselves rather than have others speak for them, is a major movement in this country. At the core of this self-advocacy movement is the power of choice. Persons who have disabilities

have had little choice in their own lives, when, in actuality, these people should be fully instrumental in their own choices.

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The ideal of an inclusive society can never be reached unless people with severe disabilities participate in choices that affect their own lives, including employment training, employment, education, and living arrangements (McDonnell et al., 1995; Pacht, 1996; Ward, 1996). Job satisfaction is an important identifying factor for many adults in the U.S. People who have severe disabilities have the right and need to job training and employment opportunities. With the support from vocational education legislation and personnel, people who have disabilities are entering employment and experiencing job satisfaction and increasing self-worth.

Self-advocacy is the strongest type of advocacy. The human spirit is diminished when people feel they have no say over their life and its occurrences (Dybwad & Bersani, 1996). Self-advocacy is essential because persons who have disabilities are frequently oppressed and treated as secondary citizens. Self-advocacy increased when persons who have disabilities grew tired of their treatment by society and began advocating on their own behalf, despite overwhelming odds ( Miller & Key, 1996; Stone, 1989).

Advocacy for individuals who have severe disabilities has evolved from being a group of parents and friends who advocate to become a movement of individuals who have disabilities to advocate for their own needs (Cohen & Livneh, 1986). Early

in the evolution of self-advocacy during the 1960s, the President's Panel on Mental Retardation issued a booklet which led to the question, "Are we retarding the retarded?" (Dybwad & Bersani, 1996). There followed a national discussion of rights for persons with disabilities, including their rights to choose a place to live, vote, marry, have children, and receive a fair trial. From these discussions, individual advocates realized the need for civil rights for persons who have disabilities - a realization already understood by people with severe disabilities.

The growth in self-advocacy has been significant over the past thirty years. In the mid-1980s hundreds of groups of self-advocates were meeting around the United States at the local, regional, and state levels. In 1990, a group of individuals from across the United States, who had been labeled as mentally retarded, attended the First North American People First Conference, now known as Self-Advocates Becoming Empowered, or SABE (Dybway & Bersain, 1996). One of this group's goals is to ensure equal employment opportunities for all people. The self-advocacy movement has developed enormous strength and power from programs such as SABE.

## Challenges of Self-Advocacy

Self-advocates face many challenges. Attitudes and philosophies towards persons who have disabilities still need to be improved. Some members of our society wonder if these individuals actually deserve all the dignity and freedom for which they advocate. The empowerment of a previously unempowered group produces a corresponding disempowerment of those previously "wielding the power" (Rosen, 1994; Stainback, Stainback, East, & Sapon-

Shevin, 1994), and this can be frightening to some.

Pragmatically, there are a number of barriers that hinder individuals who have severe disabilities in advocating for themselves. The combined effects of barriers that are physical, communicative, emotional, together with social stigma and isolation, can be significant obstacles for many individuals who have severe disabilities to overcome. Many persons who have disabilities are limited by their disability itself, such as not being able to speak or having limited mobility. These handicaps can limit the ability to self-advocate and to be heard by others. In addition, individuals who have severe disabilities, as a result of dependency upon others, may perceive themselves as more subordinate than autonomous. These factors contribute to individuals' reluctance to assert themselves to advocate for these rights (Brooks, 1991; Wehmeyer, 1992). Individuals who have severe disabilities may also see themselves in ways that prevent them from engaging in advocacy activities and questioning their own ability to self-advocate effectively. Like other minorities, people who have severe disabilities may have had limited experience with democracy. Despite these challenges, "there are wonderful advocates that work for us as people who have disabilities, but there is nothing as powerful as people who have disabilities speaking for ourselves" (Cone, 1994). Self-advocacy is a strong method of persuasion.

## Benefits of Self-Advocacy

Self-advocacy differs from individual and group advocacy in that self-advocates represent themselves. Cone (1994) observed that self-advocates attending the 1994 National Self-Advocacy Conference, the first meeting of a new national self-advocacy organization,

expressed a degree of emotion, sense of community, and fellowship that made this advocacy meeting different and powerful. A sense of urgency surrounded the self-advocates because of their shared experiences of segregation, loss of community identification, loss of familial contact, loss of jobs, and deterioration of skills and abilities due to idleness, boredom, and frustration.

Self-advocates often raise two main issues: freedom and fear. They want the freedom to choose: (1) where to be educated; (2) where they work; (3) where they live; (4) with whom to have relationships; (5) to make decisions; and, (6) to make mistakes. The primary fear for self-advocates is that they will not have these freedoms (Alper, Schloss, & Schloss, 1995; Cone, 1994).

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To be denied or discouraged from educational opportunities limits career options and employability options and to not be employable means the continuation of dependency on other and on "the system". Their fight makes the self-advocacy movement a civil rights movement for freedom, which yields empowerment. Through this empowerment one's self-concept is developed (Pacht, 1996; Ward, 1996). Empowerment implies that many competencies are already present in an individual and that new competencies are then learned in the context of experiencing daily life (Balcazar, Keys, Bertram, & Rizzo, 1996). Empowerment gives a person who

has a disability the opportunity to exercise and implement the freedoms listed above (ILSMH, 1996; Wehmeyer, 1996).

Developing a greater number of self-advocates is crucial to protecting the rights of those with severe disabilities (Zirpoli, Wieck, Hancox, & Skarnulis, 1994). Many self-advocacy training programs exist in the U.S. The vocational education movement, particularly over the past thirty years, has been a leader in training, educating, supporting, and creating self-advocates of people who have disabilities (Fabian, et al., 1998).

## Summary

Advocacy, especially self-advocacy, is a critical component for improving the lives of persons who have disabilities. Fighting for disability rights has been a long and burdensome task, and not until recently have drastic and necessary changes occurred for persons who have disabilities particularly in the areas of employment, education, and accessibility to services. Self-advocates are at the forefront of effecting these positive changes. Self-advocates put a "face with a name", making it hard for people in their community and for political representatives to ignore their demands for equal opportunities and fairness.

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Self-advocates have been instrumental in boldly bringing about change with issues of job training, access to higher education with appropriate accommodations, job recruitment and retention, and narrowing the wide-gap of low employment for people who have disabilities

(Gugerty, 1995). Career and technology education and vocational personnel have been instrumental in the self-advocacy movement. Through legislation, educational opportunities, and individual advocacy, educators and trainers in the area of vocational education have been key contributors to helping individuals who have disabilities develop job skills and the confidence to self-advocate. It is necessary and important for adults who have severe disabilities to self-advocate. Educators, employers, family, and friends are beginning to acknowledge that people with severe disabilities can advocate for themselves. These people must assist people who have severe disabilities acquire skills, training, and self-esteem to self-advocate (Cunconan-Lahr & Brotherson, 1996; Nisbett, 1992). Self-advocacy training and support should begin during the public school years and continue throughout education, job training, and employment.

As a country, we have much to do to lessen the burdens advocates have to undertake. With current government cutbacks in funding, advocacy for disability rights must continue to be strong. Individuals who have severe disabilities should not be ignorant of the opportunities and support available. Service providers should make a concerted effort to train advocates and educate them about services available to them (West, et al., 1993). Self-advocates remind all of us that persons who have disabilities are guaranteed the same Constitutional rights and privileges, as are all people.

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