

Self-Determination & Consumer Involvement

What Is Self-Determination?

For much of our history, people living with disabilities and chronic illnesses were often segregated from their communities. Placed in institutions, separated from those considered “normal”, people with disabilities had little, if any, voice in the decision-making processes of their lives. Over the last half of the 20th century, however, there was a profound shift toward the inclusion and integration of people with disabilities into the fabric of everyday lives of our communities. In recent years, home and community-based services have expanded, person-centered planning has become the ideal, and an emphasis placed on self-advocacy. Under the umbrella of self-advocacy, people with disabilities were encouraged to take control of the choices that affect their lives and take risks, as well as living with the outcomes of their choices – good or bad.

The self-determination movement was born in the 1990s, growing out of other initiatives involving disability rights and self-advocacy. Through the self-determination movement, people living with disabilities made choices about how and where they lived, whom they may need to help them reach their goals, and how they could best be supported to do so.

Self-determination does not only apply to people with certain disabilities or chronic illnesses. The movement encompasses all groups; people with long-term or temporary physical disabilities, people with mental or cognitive disabilities, and people living with age-related disabilities.

Self-determination means that people, regardless of type or severity of disability, should have the same opportunities to create their own futures and lifestyles as those without disabilities. The self-determination movement is founded on five principles

Freedom. The exercise of the same rights as all citizens. People with disabilities will choose assistance when necessary, will establish where they want to live, with whom they want to live, and how their time will be occupied. They will have their own hopes and dreams and the same opportunity to realize them.

Authority. The control over whatever sums of money are needed for ones own support, including the re-prioritizing of this money when necessary. This is accomplished through the development of an individual budget that “moves” with the person.

Support. The organization of these resources as determined with the disability. This means that individuals do not receive “supervision” and “staffing”. Rather, people with disabilities may seek companionship for support and contract any number of discrete tasks for which they need assistance.

Responsibility. The wise use of public dollars. Dollars are now being used as an investment in a person's life and not handled as resources to purchase services. Responsibility includes the ordinary obligations of citizens within the community, allowing individuals to contribute to the well being of their community in meaningful ways.

Confirmation. Confirming the important leadership role that self-advocates must hold in a newly designed system.

The foundation of self-determination, as well as consumer direction, can be traced back to the independent living movement that occurred during the 1960's and 1970s. People with disabilities asserted their rights to live as full participants of mainstream society and live independently in their communities.¹ There are **Ten Principles of the Independent Living** movement.

1. **Civil Rights** – Equal rights and opportunities for everyone
2. **Consumerism** – The person buying or using the service or product decides what is best for themselves
3. **De-institutionalization** – No one should be institutionalized on the basis of disability
4. **De-medication** – Individuals with disabilities are not “sick”, and do not require help from certified medical professionals for daily living activities
5. **Self-help** – People learn and grow by discussing their needs and concerns with people who have similar experiences
6. **Advocacy** – Systemic, systematic, long-term and community wide change activities that ensure that people with disabilities benefit from all that society offers
7. **Barrier Removal** – The removal of architectural, communication and attitudinal barriers from society which inhibit people with disabilities benefit from all that society offers
8. **Consumer Control** – Organizations best suited to work with people with disabilities are staffed and operated by people with disabilities
9. **Cross-disability** – Activities conducted by organizations supporting the Independent Living Philosophy must benefit people with all types of disabilities
10. **Inclusion** – People with disabilities must be included in society at all levels and aspects

Some Other Significant Milestones in the Self-Determination Movement

▪ **Americans with Disabilities Act (ADA)**

The Americans with Disabilities Act (ADA) was enacted in 1990 to secure the basic civil rights of people with disabilities in this country and to counteract decades of discrimination and equal access denied. Hailed by millions as landmark legislation akin to the Voting Rights Act and other anti-discrimination measures, the protections offered

¹ Scala, Marisa A. & Nerney, Thomas. *People First: The Consumers in Consumer Direction*. The Center for Self-Determination Publications. <http://www.self-determinations.com/publications.consumerprint.html>

by the ADA include guarantees of equal opportunity for individuals with disabilities in public accommodations, employment, transportation, State and local government services, and telecommunications.

▪ ***Olmstead Decision***

The *Olmstead Decision* refers to a 1999 ruling by the US Supreme Court. The ruling held that a portion of the Americans with Disabilities Act, commonly known as the “integration mandate,” requires states to provide integrated community-based services, rather than segregated, institutional services, to people with disabilities, regardless of age or type of disability, who indicate such a preference.

While the Court did not require states to implement immediate and complete overhauls of their service systems, they did suggest that a state’s compliance with the decision could be measured by the presence of a “comprehensive, effectively working plan” to provide community-based services adequate to the demand. Alabama has developed an *Olmstead Core Workgroup*, comprised of consumers and other stakeholders, that has been planning and implementing improvements to its system of community services.

▪ ***New Freedom Initiative***

President Bush announced the New Freedom Initiative on February 1, 2001, as part of a nationwide effort to remove barriers to community living for people with disabilities. Today, there are more than 54 million Americans living with a disability, representing a full 20 percent of the U.S. population. Almost half of these individuals have a severe disability affecting their ability to see, hear, walk or perform other basic functions of life. In addition, there are more than 25 million family caregivers and millions more who provide aid and assistance to people with disabilities.

The New Freedom Initiative is a comprehensive plan that represents an important step in working to ensure that all Americans have the opportunity to learn and develop skills, engage in productive work, make choices about their daily lives and participate fully in community life. The Initiative's goals are to:

- Increase access to assistive and universally designed technologies;
- Expand educational opportunities;
- Promote homeownership;
- Integrate Americans with disabilities into the workforce;
- Expand transportation options; and
- Promote full access to community life.

▪ ***Real Choice Systems Change Initiatives***

The Centers for Medicare and Medicaid Services (CMS), the federal agency that provides funding for Medicaid services in the states, has made a significant effort in recent years to promote increased choice and self-determination in home and community-based services. A series of funding opportunities, known as Real Choice Systems Change grants, have been offered to State to support: the President’s “New Freedom Initiative”; the States’ efforts to fulfill the ADA; and the long-standing desire of people of all ages who have a

disability or long-term illness to live and participate in their communities with dignity and value. Alabama has received several grants under this Real Choice initiative that have been used to promote self-determination efforts at the Alabama Medicaid Agency, Department of Mental Health and Mental Retardation, Department of Senior Services and other private agencies.

▪ **Jobs**

Employment can be a goal for *everyone* of working age. And by employment, we mean real work for real pay. Initiatives that support the employment of people with disabilities include the federal Ticket to Work program. **Ticket to Work** is a shorthand term for the *Ticket to Work and Work Incentives Improvement Act of 1999*. This new law gives people with disabilities more choice in obtaining rehabilitation and vocational services; removes barriers that require people with disabilities to choose between health care coverage and work; and assures that Americans with disabilities have additional opportunities to participate in the workforce and lessen their dependence on public benefits.

Under the Ticket to Work Program, most Social Security and SSI disability beneficiaries can, if they wish, receive a "ticket" they may use to obtain vocational rehabilitation, employment or other support services from an approved provider of their choice. The program will be phased in nationally over a three-year period. Alabama began using tickets in 2003.

The law expands Medicare coverage to people with disabilities who work. States also may permit working individuals with income above 250 percent of the federal poverty level to purchase Medicaid coverage. This provision is commonly called the "Medicaid Buy-In." Alabama is currently studying the feasibility of establishing a "Buy-In" program and implementing other work initiatives as a part of the State's Medicaid Infrastructure Grant.

Voting: A Part of the Process

Voters with disabilities face many inequalities in the voting process including fewer opportunities to register to vote, less access to the polls, poor alternatives to traditional voting, and in many cases the violation of a private vote.

Many citizens with disabilities are not even registered vote. Although the **1993 National Voter Registration Act ("Motor Voter" Act)**, requires that all disability service providers offer voter registration opportunities, many agencies are still not in compliance. Check and see if your agency is taking an active part in the Motor Voter registration effort.

What Roles Can Case Managers Play in Promoting Self Determination?

Case managers can play an important part in supporting the concept and the reality of self-determination by thoughts and deeds. Here are a few examples:

1. Sensitivity and Understanding

It is important for those of us who help people locate, manage and coordinate needed services and supports to examine our own beliefs and value systems. Like everyone else, our own beliefs are shaped by the society we grew up in and live in.

2. Commitment

Over the years, the role of disability professionals has changed dramatically. As self-determination becomes an increasingly important focus, the role of power is shifting to people with disabilities, essentially turning the case manager into a consultant. The case manager as consultant is now responsible for providing education, training and assistance so the people that they serve can make informed choices on their own. Within this new found role, the case manager must be committed to the principles of self-determination and aware of when their own actions may be a hinder rather than support the exercise of choice.

3. Language

Language is an important factor in the way information is communicated, understood and acted upon. All people deserve to be treated with dignity and respect. When we refer to an individual, we refer to the person first and then to the situation, condition or disability – if it is relevant. Use of “People First” terminology represents a change in how language has been used as an identifier in the past.

The goal is to make “People First” language the rule and not the exception. We aim to do that through example and education. We also want to help empower people with disabilities, and other groups, to reach their full potential – so people will realize that the commonly used stigmatizing identifiers are meaningless.

Labels degrade and evoke negative pictures in our heads. Labels do not address people as individuals or their abilities. Here are some examples of “People First” language as well as labels which should not be used.

PEOPLE FIRST LANGUAGE

people with disabilities
people who experience disabilities
person who has mental retardation
person who lives with disabilities
person who uses a wheelchair
person who is deaf or hard of hearing
person who is blind or low vision
she/he is short of stature
accessible or designated parking

LABELS NOT TO USE

the disabled
the handicapped
the retarded or mentally retarded
crippled
wheelchair bound; confined to a wheelchair
the deaf and dumb
the blind
dwarf or midget
handicapped parking

4. Knowledge

It is incumbent on case managers, as frontline advocates, to be knowledgeable about the needs, desires and aspirations of the people they provide services to. This core training effort is one opportunity for learning, but there are many more. Here are some more opportunities:

Self- Advocate Leadership Network

www.hsri.com

The Center for Self-Determination

www.self-determination.com

National Program on Self-Determination

<http://oid.unh.edu/self-determination/index.html>

The National Council on Independent Living

www.NCIL.org

HCBS Clearinghouse for Community Living Exchange Collaborative

www.hcbs.org

5. Empowerment

From (www.Dictionary.com), empowerment is defined as follows: To invest with power, especially legal power or official authority; to equip or supply with an ability; enable.

In terms of self-determination, this means acting to support the opportunities and abilities of people to make choices about their lives. You can:

- *Invest people with power* by your acknowledgement of their authority over their own lives.
- *Equip them with ability* to make choices by providing them with information at times and in ways that they can best use it.
- *Enable* people to take control over these choices by supporting and facilitating the decisions that make.