



PART I: INTRODUCTION TO SELF-ADVOCACY

“Never doubt that a small group of thoughtful people could change the world. Indeed, it’s the only thing that ever has.”

--Margaret Mead

Defining Self-Advocacy

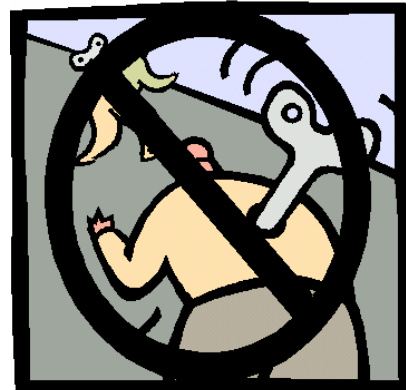
Self-advocacy means many things to different people. Here are a few ways it has been defined.

- Self-advocacy is about speaking or acting for oneself. It means deciding what is best for you and taking charge of getting it (Williams & Shoultz, 1982).
- Self-advocacy gives a “voice” to people who have not had this opportunity in the past (Bhavani, 1990).
- Self-advocacy can refer to a civil rights movement for people with developmental disabilities, which has worked alongside the bigger disability civil rights movement.
- Self-advocacy “is about independent groups of people with disabilities working together for justice by helping each other take charge of our lives and fight discrimination. It teaches us how to make decisions and choices that affect our lives so we can be more independent. It also teaches us about our rights, but along with learning about our rights we learn responsibilities. The way we learn about advocating for

ourselves is by supporting each other and helping each other gain confidence in ourselves so we can speak out for what we believe in”(SABE, 1991).

Self-Advocacy Means:

- Making your own choices
- Supporting one another
- Being your own boss
- Setting goals for yourself
- Talking about your dreams
- Helping other self-advocates
- Having control
- Sticking up for yourself



Adapted from *Self-Advocacy for Self-Advocates: A Leadership Guide*,
Center for Community Inclusion, University of Maine, 1996

The History of Self-Advocacy¹

The beginning of self-advocacy goes back to Sweden in 1968. Several national conferences were held which focused on involving the ideas of people with disabilities. This idea gained recognition, and similar conferences were held in Britain and Canada.

In 1974, several people with disabilities and their support workers from Oregon decided to attend one of the conferences in Canada. When they returned, they decided that they wanted to hold their own conference. When over 500 people attended, they decided to create a self-advocacy network. This was the beginning of People First in the United States. The early People First groups worked together to come up with models for how to develop and run self-advocacy groups.

For the next several decades new groups were being formed all over the United States and the world. Many self-advocates were helping efforts to close institutions during this time. They were also fighting many people who

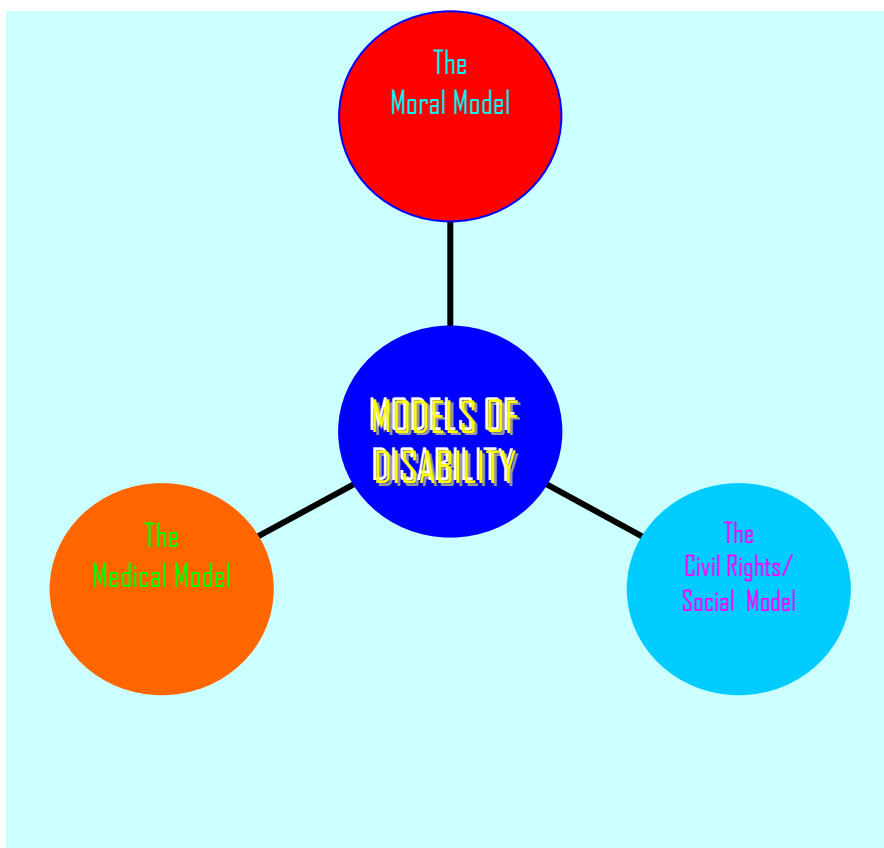
¹For an audio/visual description of the history of self-advocacy, go to the Minnesota Governor's Council on Developmental Disabilities website, Parallels in Time, to the section on "The Self-Advocacy Movement 1980's — Present" at <http://www.mncdd.org/parallels/seven/7menu.html>.

did not think that people with disabilities should be living in the community. In 1995, there were over 600 self-advocacy groups in the United States, and there were reports of self-advocates in at least 43 countries.

Today the movement continues to grow and change alongside today's times and current issues. Many self-advocates have helped make a great deal of change in their communities, and on national public policy issues. There are now self-advocates in every state across the country who are working towards self-determined lives and equality for people with disabilities.

Models of Disability

Historically there have been many different ways our society has understood and treated people with disabilities. Many of these have been harmful to the ways people with disabilities have been able to live.



These models include:

- The Moral Model
- The Medical Model
- The Civil Rights/ Social Model

Today, there are new ways of understanding disability. This next section will show you how self-advocacy fits into the civil rights/social model of disability. It is also important for self-advocates to understand the history of disability. This way they can be sure that these things don't happen again, and they can understand what goals they are fighting for.

Moral Model of Disability²

This model views people with disabilities as morally different from everyone else. This model often gives people with disabilities labels that make them different from everyone else, as being “bad” or “special.”

Disability as “bad”

- Having a disability has been thought to be “sinful” for thousands of years. Some people thought that having a disability was God’s punishment for sin.
- This fear that society had about people with disabilities as being evil or dangerous led to poor treatment of people with disabilities. This has

²Information gathered from “Villains and Charity Cases: The Moral View of Disability” ACT Memo, August 4, 2004. For a full copy of this memo, go to: http://www.selfadvocacy.com/sarn/sarn_2004August4.htm

often come in forms of segregating people with disabilities from the rest of society, letting people with disabilities be set on display to be made fun of in public (freak shows), and violence against people with disabilities.

- Today many books, movies, and even the language that people use tell us that people still think disabilities are bad. Think about evil monsters or villains in stories that have disabilities. Or the words that hurt people with disabilities that many people still use.

Disability as “Special”

- Some people who did not think that disability was sinful, instead stereotyped people with disabilities as “holy innocents,” or special souls worthy of charity.
- This was supposed to help the people with disabilities have better lives and let the people who give charity get to heaven.
- Letting people with disabilities be seen as special takes away from looking at them as regular people.

- This attitude also promotes segregation, because “special” people are treated differently.
- When people with disabilities are given charity and treated as special, they lose control over their own decisions. They are often not empowered to decide things for themselves, and service providers have control.

The Medical Model of Disability³

This model understands disability as something that is broken and needs to be fixed by experts. Disability becomes described as a “medical condition” or a “physical problem” located in the body. This attitude gives experts power, because they are supposed to know how to best “fix” the patient.

Disability as a something that needs to be “fixed”

- There have been different ways that the use of the medical model to treat people with disabilities has affected people with disabilities.

³Information gathered from “Understanding the Medical/Professional View of Disability” ACT Memo, August 14, 2004. For a full copy of this memo, go to: http://www.selfadvocacy.com/SARN/sarn_2004August18.htm

The first is that doctors have attempted to find causes and cures for disability. Today there are many behavior modification plans and drugs to get people to behave more “normally.”

- These models in some cases have been used to improve the lives of people with disabilities. This has included changing the way people live or are educated.
- Other professionals sought to improve society by getting rid of people with disabilities. This has resulted in segregating people with disabilities.
- The medical and professional fields have created research and started many services which have improved people’s lives. However, many people had to be research subjects to get these services. People are now learning that progress can only be made when people’s dignity is respected.
- The attitudes people have are very difficult to break down under this model. There is a great deal of money that is at stake under the

medical model. Individuals must be labeled and diagnosed in order to receive services.

- We can help begin to take apart the power of the medical model by educating ourselves and others about its negative effects.

Civil Rights Model of Disability⁴

This is the powerful idea that people with disabilities are regular people with the same civil rights as all other citizens. This view says that people with disabilities do not need to be fixed, instead society needs to be fixed. People with disabilities need to work together to demand and reclaim their rights.

People with disabilities are individuals who have rights

- Along side other civil rights movements for women, African American, and gay and lesbian, people with disabilities are working for their rights. All these social movements have fought similar problems such as: discrimination, lack of civil rights, oppression, and segregation.

⁴Information gathered from "The Civil Rights View of Disability" ACT Memo, September 15, 2004. For a full copy of this memo, go to: http://www.selfadvocacy.com/sarn/sarn_2004September15.htm.

- Together people within the very big category of “disabled” have been working towards issues such as dignity, self-determination, shared leadership, and inclusion.

Where does self-advocacy fit in, and what rights are we claiming?

- Self-advocacy is a part of the disability rights movement. Many people with cognitive and developmental disabilities feel that there are important injustices that they face that are different than other people with disabilities. Therefore these people decided to work alongside the disability rights movement and become self-advocates.
- **Dignity:** We do not accept labels. Moral and medical labels are rejected such as patient, sick, special, retarded, sinner, or object of fear. We claim the obvious: We are people.
- **Self-Determination:** People with disabilities have historically been denied the right to make decisions about their own lives. Now people are making their own decisions about where and how they

live. These are rights that make each person human and help coin the phrase: “nothing about us without us”

- **Leadership:** People with disabilities are fighting to have shared leadership over services and organizations which affect them. Each person becomes empowered to contribute to the vision of the self-advocacy movement.