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Self-Advocacy 101: A Tutorial

1. Definitions and Philosophy of Self-Advocacy:

Self-Advocacy means speaking up for yourself about the rights and responsibilities in your life. The philosophy of the Self-Advocacy movement is not limited to those with disabilities. Self-determination over one's life is a universal theme, which people with disabilities have taken to heart and have used to gain access to what society has to offer.

2. Background and History:

The Self-Advocacy and People First movement began in Sweden during the 1960's. Under the leadership of Dr. Bengt Nirje the Swedish Association for Persons with Mental Retardation organized a club, comprised of people with mental retardation and people without mental retardation. The club's mission was to provide recreational activities that would avail their developmentally disabled members to decide on the activities of their choice, and would then come back to the group to discuss their experiences.

Nirje's ideas were to assist the group in developing the concepts of "dignity of risk" as well as becoming more familiar with taking control over their lives. He came up against resistance from other professionals and parents who felt that the risk was too high, and that people with developmental disabilities were not able to make their own decisions. Dr. Nirje stood firm, and was quoted as saying, "To be allowed to be human means to be allowed to fail."*

Seeing the effort and effects that came about for the participants of this club, parents and members put together the first national conference in Sweden to address issues of interest related to self-determination. These efforts were beginning to be recognized and introduced in other countries such as England, Canada, and then into Oregon. In 1973 the first self-advocacy conference was held in British Columbia, with advocates attending from the Northwest, U.S.

In the following year, Oregonian Self-Advocates held their first self-advocacy conference. It was at this conference, that one of the attendees stated he didn't want to be labeled as mentally retarded, and that he was a person first! Thus, the name "People First" became the clarion call for the movement that was gaining strength worldwide. That conference was attended by over 600 people from all over the United States and set the stage for community organizing efforts nationwide. According to the most recent survey of People First Chapters, which took place in 1995, there were over 600 chapters nationwide. (Source: *Minnesota's Governor's Committee on Developmental Disabilities*)

Throughout this time, as groups were gaining strength, larger organizations were being formed to increase the power behind the voices of these groups. Issues such as institutionalization, employment training, and civil rights were challenging self-advocates to become a vocal and political force to be reckoned with. Groups like S.A.B.E. (Self-Advocates Becoming Empowered) and The Arc provided support to assist advocates in their journey towards self-determination and independence. Most recently, the 7th National conference of on Self-Advocacy, which was held in Anaheim California in 2004, had over 1400 Self-Advocates attend from locations throughout the United States and Canada.

3. Challenges:

The many challenges that advocates face are multi-faceted. For those individuals who have experienced stereotyping, lowered expectations by their "support" systems, accessing information and actual support for becoming an advocate can be compromised. Agency and governmental paternalism has been a challenge for Self-Advocates, as they begin to press for more independence, and access to training and empowerment tools. This has been changing, as providers begin to see the inherent value in self-advocacy and self-determination, as well as the economic value.

Another challenge that advocates face is the inaccessibility of information. Providing information, whether through the Internet, training tools or in the verbal form is essential, but it is often hard to gage the impact or whether people understand what is being said. Using "People First" language, and universal design in preparing information is a practical approach to this concern. Offering computer literacy training to advocates, as well as having consumers take part in the design of the training tools will undoubtedly assist in this effort.

It is also important to know what Self-Advocacy isn't. Advocacy isn't:

- Substituting your beliefs as an advocate for the belief of others
- Creating conflict for its own sake
- A chance to get even for past wrongs done to you
- An opportunity to make yourself feel powerful at the expense of others

(Source: Washington Protection and Advocacy)

4. Nuts & Bolts of Self-Advocacy:

There are many types of Self-Advocacy, depending on the source, as well as the nature of the advocacy that is being accomplished. This tutorial will focus on the strategies that the "People First" movement utilizes in their work. (Sources: "More Thoughts on Self Advocacy: The Movement, The Group, and the Individual" by Bonnie Shultz; "Advocacy Skills" Brain Injury Resource Center.)

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Personal Stories

This section includes stories of individuals with disabilities and/or their families who are living or striving to live self-determined lives within their communities. Each individual is unique and is experiencing different issues, challenges, barriers, and successes.

Read more: ["Personal Stories from the Community"](#)

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They are:

- System Advocacy
- Legal Advocacy
- Legislative Advocacy
- Individual Advocacy
- Group - Team Advocacy

Before we approach the individual types of advocacy, you might ask why self-advocacy so important? Simply put, it helps a person to achieve their goals and interests. It also is an effective way of building good problem solving and critical thinking skills that we all need in today's world. It also helps when a person is faced with discrimination, as well as resolving accessibility issues. Lastly, it can be useful in one's every day life, when dealing with family and friends, as a way of taking control of your life. The results help a person to develop a sense of self, confidence and building a future for themselves. The five types of advocacy listed above build on these ideas.

System Advocacy:

This is a strategy that looks a how a person can affect change in the way services, and laws are provided. For instance in New Mexico, the government, as well as the people or "stakeholders" who are involved with the Developmental Disabilities Waiver Program, are looking at ways to make the system works better. Because of strong advocacy on the part of statewide advocates, consumers, providers, (organizations, individuals, and agencies), the move is towards a more "self directed" approach, where people with disabilities will have more of a say in choosing services. Often times, people who are involved with this type of advocacy will use several methods to achieve this goal. They might try such things a: lobbying elected officials to hear their point of view. Letter writing campaigns are often used to campaign other officials, or people in power to get their attention on these matters.

Legal Advocacy:

As with most types of advocacy, there is some overlap in the nature of the issue, as well as the strategies we use to create change. Legal Advocacy looks at how laws are being interpreted, and if everyone is being accorded the same rights. The American's with Disabilities Act is a good example of legal advocacy. People throughout the country have used this law to counter the various efforts by society or businesses to keep people with disabilities from full community participation. Since the law has been enacted, challenges have also occurred on a regular basis, which has caused a deep vigilance of people with disabilities. Activists have had to use many types of advocacy to keep the laws in place. Legal challenges have gone through the various levels of the legal system, as well as passing other federal laws such as Olmstead and label laws to protect people with environmental and allergy based conditions.

Individual Advocacy:

As opposed to Self-Advocacy, which is defined as advocating for oneself, individual advocacy is advocating for someone else on a one to one basis. This may include such things as: understanding and interpreting medical information, or if a person is having trouble with their landlord. It is basically supporting an individual in times of conflict or if they do not understand the situation at hand. This person can mediate for a solution for a person who otherwise might not understand the full complexity of an important issue.

Group-Team Advocacy:

Team Advocacy is an effort that a group of people undertake together, using the power of numbers to affect change. It is usually done by an organized group such as People First, or SABLE, which have organized chapters, using specific techniques to accomplish their goals. It requires the development of good communication as well as being focused, prepared and with a good working attitude towards each other. It requires that although people have individual ideas about the problem, the solution one that is accepted and voted on by the group, leaving individual agendas aside in order to be successful.

