

WHAT IS SELF-ADVOCACY?

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 teaches us about our rights, but along with learning about our rights, we learn about our responsibilities. The way we learn about advocating for ourselves is by supporting each other and helping each other to gain confidence to speak out for what we believe in (SABE, 1991)." As a verb, *self-advocacy* is about advocating – lawyering– for yourself; instead of someone else (like an advocate) speaking for you. As a noun, it generally describes the grassroots, civil rights movement of self-advocacy including its associations and groups.



A Short History of the Self-Advocacy Movement:

The seeds of the self-advocacy go back to 1968 when a Swedish parent's organization held a meeting for people with developmental disabilities. The people at the meeting made a list of changes they wanted made to their services. Over the next five years meetings like this took place in England and Canada. In 1974, a small group of people from Oregon went to one of these meetings, but felt professionals were in control of it. So, they started to plan their own conference that would be run by people with disabilities. 560 people came and when a second one was held the next year, there were 750 attendees. Within five years, Oregon had 1000 members of self-advocacy groups, three different states had a growing membership, and people from 42 other states were asking for assistance to start similar groups. Today, the self-advocacy movement, as it has come to be known, has grown into an international movement in 43 countries, with an estimated 17, 000 members-plus. In the US alone, there are estimated to be well over 800 self-advocacy groups.

People First:

The People First movement started in Oregon on January 8th, 1974 at a conference planning meeting. At the meeting one person talked about being labeled "mentally retarded" and said, "I want to be known as a person first!" "People First" was chosen as the name for the convention. Along similar lines, the expression, "label jars, not people!" is often used in the movement to mark a rejection of professional labeling of people with disabilities. Many self-advocacy groups call themselves People First of, for example, Canada. But, many groups have other names like, Speaking for Ourselves and Advocates in Action. They are all part of the movement.



Self Advocates Becoming Empowered:

Self Advocates Becoming Empowered (SABE) is the US national self-advocacy organization. It was formed in 1991 and describes itself as an "active organization that is like a family." It has 18 elected board members who meet four times a year in different cities. Some of the things that the board does to forward the movement include: *Advocacy Action*—keeping members up-to-date of various advocacy opportunities; the *Campaign for Freedom*—working to push for closing institutions; *Self-Advocacy Development*—supporting people who want to find out more about self-advocacy and start state organizations; and *Public Relations*—putting out newsletters, membership information, making videos, and most recently a music CD.

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RESOURCES

BOOKS

New Voices: Self-Advocacy by People with Disabilities. (1996). Edited by Gunnar Dybwad & Hank Bersani, Jr. To date the most thorough account of the self-advocacy movement, "New Voices" covers the US and international self advocacy history, experiences of movement leaders and their support persons, and its legacy.



We Can Speak for Ourselves: Self-Advocacy by Mentally Handicapped People. (1982). by Paul Williams & Bonnie Shultz. The first historical account of the self-advocacy movement, this book looks at its origins; tells the stories of its development in Nebraska (Project Two) and Britain with input of the first members there; describes its principles, a self advocacy curriculum, and resources; and, finally, includes numerous personal stories of many people with disabilities who were leaders and the first members of the movement. Order both books from: Brookline Books, P.O. Box 1047, Cambridge, MA 02238-1047, 1-800-666-BOOK

SABE RESOURCES



Close the Doors Campaign Kit, a set of materials by SABE Board members about how to work for closure of institutions in their own states or elsewhere. Order from: Center on Human Policy, Syracuse University, 805 S. Crouse Ave., Syracuse, NY 13244-2280, 1-800-894-0826.

Respect CD or Cassette. Made by songwriter Karl Williams, the Self Advocates Becoming Empowered Board of Directors and advisors in 1997, this is a powerful collection of 14 self-advocacy songs including "Stand Together," "Speaking for Ourselves," "Close the Doors," and new songs. Order from: SABE, P.O. Box 15165, Loves Park, IL 61132.



CENTER ON HUMAN POLICY RESOURCES

Materials on Self-Advocacy (1997) by Rachael Zubal, Bonnie Shultz, Pam Walker and Michael Kennedy includes an overview article, a short listing of information available, and selected reprints.

A Chance To Be Made Whole: People First Members Being Friends to Tear Down Institution Walls (1997). This booklet is the summary of a meeting of People First of Tennessee members and advisors compiled by John O'Brien. It presents, in their own words what people have learned about reaching out and being friends to people who still live in institutions, and about supporting them to move out into the community. Order both resources from: Center on Human Policy, Syracuse University, 805 S. Crouse Ave., Syracuse, NY 13244-2280, 1-800-894-0826.

THE ARC RESOURCES

Self-Advocacy Bibliography. This detailed bibliography lists several resources on self-advocacy. Single copies free, if requested. Order from: The Arc, 500 East Border Street, Suite 300, Arlington, TX 76010, (817) 261-6003, <http://TheArc.org/misc/sabib.html>



INTERNET RESOURCES

New York State Self-Advocacy Association - <http://www.capital.net/~sanys/>

Northamptonshire People First - <http://www.peoplefirst.org.uk/>

Advocates in Action—Rhode Island State Association, host of the 2000 national self-advocacy conference - <http://www.aina-ri.org/>

Advocating Change Together - <http://www.selfadvocacy.com/>

Speaking for Ourselves—Pennsylvania State Self-Advocacy Association - <http://www.libertynet.org/speaking/speak.html>

Roehrer Institute - <http://indie.ca/roehrer>

Self-Advocacy Resources from the Center on Human Policy - <http://soeweb.syr.edu/thechp/selfadvo.htm>

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