



OPEN SOCIETY INSTITUTE MENTAL HEALTH INITIATIVE

Self Advocacy for People with Mental Disabilities

Background

What is self advocacy?

Self advocacy means people with disabilities speaking up for themselves, making decisions about their lives, and taking action to claim their rights.

Kinds of self advocacy

Individual self-advocacy is about people with mental disabilities taking control over their own life. People with mental disabilities can say how they want to be treated and what they want to do. They can tell professionals and others what they need and how they want to live their lives.

Group self-advocacy is about people with mental disabilities working together to change the way people with mental disabilities are treated by others. People with mental disabilities can have a more powerful voice if they support each other in speaking up for their rights. They can help shape policies and laws that affect people with disabilities, and can help people without disabilities understand people with mental disabilities better.

Why is self advocacy important?

People with mental disabilities are often left out of decisions affecting them. They are not heard or are not taken seriously. They are often told what to do without being asked what they want for themselves. They are often not allowed to decide how they should live their lives. This makes people with mental disabilities feel dependant and unimportant. But their opinion is important, because no one else knows better what people with mental disabilities want. This is why professionals, activists, and decision-makers working with people with mental disabilities should listen to what these people have to say.

What can self advocates achieve?

Self-determination: People with mental disabilities can take control over their own life, make their own choices and have their own voices heard when decisions about them are made. They can speak up against abuse, neglect, and ignorance.

Setting examples: Self advocates give support to other people with disabilities and encourage them to become advocates themselves. They also show people without disabilities that people with mental disabilities can speak for themselves and should be listened to.

Educating others: Self advocates can help people without disabilities understand people with disabilities better. They can raise awareness of the needs and rights of people with mental disabilities and can receive recognition and respect for who they are.

Empowerment: Self advocates learn about their rights and about ways to fight for them. They learn how to become leaders and how to change policies, laws, and practices for all people with disabilities.

Breaking barriers: Self advocates fight against discrimination and stigma. They can ask that people with mental disabilities live, learn, and work together with people who do not have disabilities.

History

The self advocacy movement started in Sweden in the 1960s, when a group of people with intellectual disabilities wrote down a list of requests about how their services should be provided. They gave the list to the parent organization that supported them and asked to be included in the parent organization's advocacy efforts. Now the self advocacy movement is alive and growing. It is an international movement with more than 17,000 members in 43 countries.

Self Advocacy in Practice

What do self advocates do?

Testifying: Self advocates can tell others about what life is like for people with mental disabilities. They can expose abuse and neglect. They can tell professionals, services providers, activists, and others what they want and what they do not want.

Monitoring and documentation: Self advocates can check how people with mental disabilities are treated. They can help write down or collect documents on the lives of people with mental disabilities so that their successes and problems can be known to people who make decisions and to everybody else.

Exploring options: Self advocates can help each other understand what needs to be done to make the lives of people with mental disabilities better. They can ask for help from other advocates and professionals without disabilities in gathering information about possible ways to change the situation and about possible solutions to problems. They can then decide what they want to do for themselves.

Building support: Self advocates can work with families, friends, and disability groups to build support for what they want to achieve. They can talk to other groups which face discrimination or fight for human rights to make the voices of people with mental disabilities stronger and to make sure that people with disabilities are never alone when they claim their rights.

Mobilizing for action: Self advocates can act on behalf of people with mental disabilities by organizing campaigns. They can mobilize people with disabilities and their allies to say what they want in letter-writing or telephone campaigns, direct meetings with decision-makers, events which are meant to raise awareness, protest demonstrations, etc. They can speak to the media or to people making decisions affecting people with mental disabilities.

How do they do it?

Self advocates learn about their rights and acquire skills to speak up for themselves. They can learn these things from other self advocates or from people without disabilities who want to support them (other activists, families and friends, personal assistants).

Self advocates ask for support when they need it and say how they need to be supported, but they do not let others make decisions for them. Self advocates help themselves decide what to do and how to do it. They make their own plans for action and follow them.

People with mental disabilities can set up groups that support them to speak for themselves. These self advocacy groups can be registered organizations, or simply groups of people that meet to discuss problems and solutions.

Self advocates try to speak up every chance they have. They understand that it takes a long time to make changes and that people without disabilities need to be told very often what people with mental disabilities want.

Some problems that self advocates have and how to deal with them

Isolation: Sometimes people with mental disabilities feel isolated and segregated. They find it hard to make their voices heard beyond self advocacy and disability groups. Self advocates fight such separation by talking to other allies and by actively seeking chances to represent people with mental disabilities before people without disabilities.

Unfairness: Some people with mental disabilities are unfairly excluded from self advocacy work. Some people think that self advocacy is only for those people with mental disabilities that have less need for support or have an easier time communicating with people without disabilities. It is true that self advocacy might more difficult for some people with mental disabilities, but this does not mean that they should not be included. Self advocacy can help lower the support needs of some people with mental disabilities, and can help them communicate better and become more independent. For those people with mental disabilities for whom it is dangerous or impossible to speak out for themselves, other people with disabilities are the best spokespersons.

Ignorance: Some self advocates feel that people without disabilities do not listen to them, or do not take them seriously. This sometimes happens because people without disabilities are not used to talking to people with mental disabilities or to being told what people with mental disabilities want. Some people without disabilities may even think that people with mental disabilities have no right to speak up. This is not true. Self advocates know that people with mental disabilities have been isolated and have not allowed to speak up for themselves for a long time, but they also know that people with mental disabilities do have rights, and should be listened to. Self advocates know that courage and patience are needed to get people without disabilities used to listening to people with mental disabilities.

No money: People with mental disabilities are often poor. They are often afraid that they cannot be self advocates because advocacy work costs too much money. But this is not true, because people with mental disabilities can do a lot of things to help themselves without spending any money. They can meet and discuss problems and solutions by themselves, they can write letters, talk to people making decisions in their area, or protest in the street without spending much money. They can ask their friends, families, and allies to help them out by making phone calls, writing e-mails, or offering to volunteer support for self advocacy work. They can even ask other groups and allies to volunteer to help them raise money for campaigns.

Select resources

Protection and Advocacy, *Introduction to Self Advocacy* (Sacramento, CA:1990), a step-by-step guide for self advocates is available in English at: <http://www.pai-ca.org/PSA/PAI%20Advocacy%20Publications/INTRODUCTION%20TO%20SELF-ADVOCACY%205070.01.HTM>

People First UK offers an easy-to-read introduction to self-advocacy in English at: http://www.peoplefirstltd.com/new_page_1.htm

British Columbia Self Advocacy Foundation, *Self Advocacy Group Starter Kit: How to Start a Self Advocacy Group* (Vancouver, BC: 2001) is available in English at: http://www.selfadvocatenet.com/useful_tools/default.asp

Bonnie Shoultz, *The Self Advocacy Movement*, a succinct introduction to the self advocacy movement and its history, is available at: <http://www.thearc.org/faqs/samove.html>

A series of English-language materials on self advocacy prepared by Rachael Zubal, Bonnie Shoultz, Pam Walker, and Michael Kennedy in 1997 are available at: <http://thechp.syr.edu/matonsa.htm>

Pentru Voi, *Auto-reprezentare* (Timișoara, Romania: N.D.), a Romanian-language introduction to self advocacy, is available at: <http://www.pentruvoi.ro/publicatii/auto-reprezentare.pdf>