

The Key

the
Clearinghouse
at MHASP

Assistance Report
focus on—**SELF-ADVOCACY**

SUMMER 2004

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Self-Advocacy Training Offers Hope to Many

Speaking at a conference hosted by a state mental health department's office of consumer affairs, a young woman told a story that moved several audience members to tears. The woman, who also had developmental disabilities and had lived in group homes for her entire adulthood, spoke about a personal victory. She had not only won a needed service, but she had also won respect.

For quite some time, she had lived in a group home that did not have a telephone, and she and her fellow residents had been required to use a pay phone. It was difficult to afford to make calls on her tight monthly allowance, and the need for correct change was an inconvenience. Even worse, service providers, friends, and family had difficulty reaching her. Although she was living in the community, she felt isolated.

Unhappy with the inconveniences of the pay phone, she asked the group home's staff why the home did not have a telephone. Not satisfied with the response she got, she kept going, arranging meetings with the owner of the group home and with staff members of the local agency that oversees group homes. Over and over, she stressed how important it was to have a telephone. Initially, she encountered disappointments as she tried to have this basic need met. However, she kept going in the face of adversity and, after several meetings, a telephone line was finally installed in the group home. For the first time, she had stood up for herself, and her persistence had paid off.

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Her descriptions of facing her fears and overcoming them were particularly poignant; however, her story is far from unusual. Many people with disabilities have found that in order to obtain the services and supports they need for recovery, they must engage in self-advocacy. At its most basic level, self-advocacy means standing up for oneself and communicating needs effectively—skills that can be learned.

Despite the many people who act as individual advocates for consumers—including case managers, peers, friends, family members, and professionals—the need for self-advocacy is great. Individual advocates often must help many people at once, and sometimes advocates' ideas of what is best do not match their clients' ideas. In the wake of the U.S. Supreme Court's *Olmstead* ruling, which requires states to provide services in the community rather than

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Welcome to the new Key Assistance Report, the first in our quarterly series of technical assistance products designed to help consumers everywhere get what they need. This Report evolved out of the Key newsletter, along with our new monthly Key Update. Each Key Assistance Report will stand on its own as a concise toolkit of discussion and resources focusing on a specific topic in consumer self-help. Upcoming Reports will focus on such issues as employment and stigma and discrimination.

The Key Update, our monthly e-newsletter, provides late-breaking news and notes on important mental health issues through our e-mail listserve. To receive the Key Update go to www.mhselfhelp.org/contact.html or send e-mail to majordomo@majordomo.dca.net. In the body (not the subject) of your e-mail enter 'subscribe thekey' on one line and 'end' on the next. If you don't

institutions, and with current budget shortfalls in most states, advocates are often under pressure to help more and more people.

Many seasoned advocates have discovered that the best way to advocate for someone is to teach that person how to advocate for himself or herself. Often, the first step is developing confidence. "A lot of people are trapped in a pattern of learned helplessness. They're caught up in allowing people to do things for them and make decisions for them," said Stephanie Mitchell, assistant director of the Pennsylvania Mental Health Consumers' Association (PMHCA). By stressing the need to develop self-advocacy skills, advocates can help people break out of the pattern described by Mitchell.

Although many advocates teach self-advocacy skills "on the job," as they are helping people resolve specific problems, another effective method of teaching self-advocacy skills is to offer formal training. Successful self-advocacy does not require extensive knowledge of legal concepts or complicated strategies. In fact, by focusing on basic concepts that people can learn easily and apply right away, self-advocacy training can have an immediate impact on people's lives. One self-advocacy educator (who did not want his name used in this article) recalled, "In one of my workshops, the group was discussing some of the problems they had encountered in their relationships with their doctors. One young man mentioned that he had repeatedly asked his psychiatrist to change his medications because he was having trouble sleeping.

However, she had refused to prescribe anything that would help him sleep. I suggested that he keep a log of the hours that he had slept and bring it with him to his next appointment.

"Two weeks later, at the next workshop, he proudly reported to the group that his psychiatrist had finally listened to him and

changed his medications after he gave her the sleep log that he had kept. The group was surprised that he had gotten such quick results, but I wasn't really that surprised. I had used the same strategy myself, and my doctor had changed my medication."

Ten Hints for Successful Self-Advocacy

Everyone is capable of some form of self-advocacy—even those who find the idea of speaking up for themselves intimidating. Here are a few hints taken from the Freedom Self-Advocacy Curriculum to help you get started:

1. Believe in yourself. Remember that you are someone who is worth advocating for. You can accomplish a great deal, even if you are used to people telling you what you can't do.
2. Define your needs. Before you start contacting people, make sure you can explain exactly what you need. Sometimes it's a specific service but, other times, you could just be looking for an apology. Be as specific as possible in what you ask for, because it is much easier for someone to agree to your request than it is for that person to find something that will meet your needs.
3. Seek out problem-solvers. Target people who have the ability to make decisions or influence people who do. If someone tells you that he or she has no control over a situation, find out who does and talk to them. People who did not cause a problem might be able to solve it for you, so take a positive approach.
4. Do a reality check. Sometimes we are so convinced that we are right about something that we can't see the other side. Bouncing ideas off a trusted friend can help you see where your case is strong and where it's weak.
5. Practice beforehand. Practicing with a friend can help you plan what you are going to say and how to respond to questions. Even practicing in front of a mirror can be helpful because watching oneself act assertively can build self-esteem.
6. Find an outlet for your anger. While it is important for people to understand your anger, it is not always helpful to let them see it in action. Successful self-advocates have found ways to let off steam such as having a friend nearby when making an unpleasant phone call and making faces together.
7. Promise yourself a reward for unpleasant tasks. Picking up the phone, writing a letter, or bringing up a difficult topic can be less daunting if there's a reward waiting—even something as simple as a candy bar.
8. Practice active listening. Let people talk, but don't remain completely silent. Ask questions when someone uses a term or an abbreviation that you don't know. To avoid confusion on important points, restate the person's position: "So what you're saying is . . ."
9. Stick to the facts. People are more likely to be swayed by hard facts than they are by your opinion. For example, pointing out that a therapist has cancelled three appointments on short notice makes more of an impact than saying, "My therapist is unreliable."
10. Follow up and send thank-you notes. Self-advocacy is about building relationships, and it's important to let people know that you appreciate their help. It's also important to make sure people follow through with what they've promised. Follow up a telephone call or meeting with a thank you note, and summarize what you've agreed upon: "Thank you for agreeing to . . ."

Many self-help and mutual support groups, in addition to providing emotional support, now focus on providing support for self-advocacy. While working in a previous position for a service provider in Pennsylvania, Mitchell convinced her supervisor to allow her to offer self-advocacy training and run support groups in the agency's residential facilities and other programs. The

results were impressive: "We ended up with a network of self-advocates within the programs. It was really beautiful," she said.

Mitchell recalled a story illustrating how support groups can provide ideas and inspiration for successful self-advocacy. One of the support group members had been

living at a residential facility in a room infested with insects. "He had been told time and time again that it was not that big a problem," said Mitchell. However, the infestation was making him miserable. He discussed the problem with his self-advocacy support group and, based on the discussion, he started writing down when the bugs were coming in and taking pictures of them. According to Mitchell, his hard work paid off. "Soon he had a whole report that he handed in to the director of the program. The problem was fixed a week later because there was nothing the director could say when he was confronted with the facts," she said.

Self-advocacy is catching on, even in some unexpected places. Berni Grajek teaches self-advocacy at a consumer-run drop-in center in Guam, a U.S. island territory located in the Pacific near the Philippines and Indonesia. Grajek said that teaching self-advocacy in Guam presented some unique challenges. She described locals—primarily of native Chamorro, Filipino, and Asian origin—as generally being "non-aggressive." In fact, she said, when she started teaching self-advocacy workshops, "Nobody knew what the word 'advocacy' meant. It was very difficult for people to grasp the

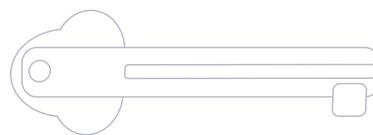
"Nobody knew what the word 'advocacy' meant. It was very difficult for people to grasp the concept . . . Typically, whatever the doctor said, you did it."

concept of questioning their doctors. Typically, whatever the doctor said, you did it."

After teaching several self-advocacy workshops, she has helped people to retain and improve their self-advocacy skills by periodically reviewing lessons from the workshops and asking how people have applied the lessons in their own lives. Over time, she noticed dramatic results. "Now, everybody knows the names of their medications, why they're taking them, and what the side effects are," she said.

In addition to leading ongoing self-advocacy support groups, Grajek and Mitchell have both used the Clearinghouse's Freedom Self-Advocacy Curriculum as an instructional tool. The train-the-trainer curriculum, complete with a teacher's guide and handouts, makes teaching self-advocacy skills easy. The three workshops include overviews of key strategies for self-advocacy and interactive activities for practicing these skills. The curriculum is modular, allowing the instructor to choose from among several activities, depending upon the needs and interests of the audience. The curriculum materials are available at no charge on the Clearinghouse Web site, <http://www.mhselfhelp.org>.

Mitchell believes that the importance of self-advocacy training cannot be overstated. "I see self-advocacy as the route to recovery, and once people are trained how to make their own choices and advocate for those choices, their future looks a lot brighter."



Other Self-Advocacy Resources

The National Mental Health Consumers' Self-Help Clearinghouse offers the Freedom Self-Advocacy Curriculum as well as advice about self-advocacy. Be sure to check out these other resources:

Bazelon Center for Mental Health Law

<http://www.bazelon.org> (202) 467-5730

The Bazelon Center is a public interest law firm advocating for the rights of mental health consumers. It cannot provide individual legal advice, but offers several helpful self-advocacy publications, including *Arrested? What Happens to Your Benefits If You Go to Jail or Prison?* and *What "Fair Housing" Means for People with Disabilities*. These publications are written for consumers and are available free online, and in print for a modest fee.

Mental Health Services Research Program

<http://www.psych.uic.edu/mhsrp/> (312) 422-8180

The Mental Health Services Research Program of the University of Illinois at Chicago is a research and training center funded by the National Institute on Disability and Rehabilitation Research (NIDRR). The program offers several useful "Self-Determination Tools," including *This Is Your Life! Creating Your Self-Directed Life Plan* and *Raising Difficult Issues With Your Service Provider*, which are available free both online and in print.

National Mental Health Association (NMHA)

<http://www.nmha.org> (800) 969-NMHA

The NMHA is a mental health advocacy and education organization with over 300 affiliates nationwide. It has developed a useful self-advocacy tool for people taking antipsychotic medication: the *Antipsychotic Side-effects Checklist* is an in-depth tool listing potential side effects of antipsychotic medications and allowing the user to rank and evaluate these side effects to facilitate discussions with health care professionals.

National Mental Health Information Center

<http://mentalhealth.samhsa.gov/> (800) 789-2647

The Substance Abuse and Mental Health Services Administration (SAMHSA) provides information about mental health via a toll-free telephone number, Web site, and more than 600 publications. Helpful self-advocacy publications include *Speaking Out for Yourself: A Self-Help Guide*, by Mary Ellen Copeland, and *Choosing the Right Mental Health Therapist*. These publications are written for consumers and are available free both online and in print.



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Alternatives 2004

*Achieving the Promise of Recovery:
New Freedom, New Power, New Hope*

October 13-17, 2004
Denver, Colorado



The National Mental Health Consumers' Self-Help Clearinghouse is pleased to present Alternatives 2004 in beautiful Denver, Colorado.

In its 19th year, the Alternatives conference is the only national mental health conference organized by and for consumer/survivors. Each Alternatives conference offers in-depth technical assistance on consumer/survivor-delivered services and self-help/recovery methods.

This year's theme is "Achieving the Promise of Recovery: New Freedom, New Power, New Hope." The President's New Freedom Commission on Mental Health recently called for transforming mental health systems to make them consumer-centered and recovery-oriented. Alternatives offers the opportunity to share in this vision.

For more Alternatives 2004 information contact:
Horizon Meetings, Inc. (800) 776-1286,
or visit www.mhselfhelp.com/alt2004.html for online registration.

Alternatives Alert!

Room availability is running low! Pre-conference registration rates end October 1, 2004. Act soon to reserve your place!



This Key Assistance Report is a technical assistance product of the National Mental Health Consumers' Self-Help Clearinghouse, which is solely responsible for its content. We encourage copying and distribution of this Report to all who may be interested.

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