

1. Advocacy

ISSUES:

Over the last 30 years, consumers/survivors have spoken out strongly, both for their own individual rights and to effect systems change. However, many barriers to advocacy still exist, and there is an enormous need for advocacy education along with ongoing support to consumers/survivors to ensure that a knowledgeable, strong, visible and vocal grassroots movement is built.

- **Self-advocacy**

BACKGROUND:

Many individuals do not know their rights and may be fearful that they will be labeled as troublemakers or not receive services if they challenge the system. Stigma and long-term hospitalization have often stymied consumers' abilities to determine the course of their lives. Self-advocacy education helps individuals speak out on their own behalf by giving them the tools and skills necessary to empower themselves to play a central role in shaping their lives, which includes making treatment decisions as well as deciding what type of services they receive. Mastering these skills and acquiring confidence can often lead an individual into complex — and necessary — systems advocacy.

Advocacy begins with *SELF*. Self-advocacy education should encourage a person to gain self-knowledge of what he/she needs to maintain mental stability and build a strong personal support system. Education should include information on patients' rights, disability laws, how to access available services and resources, legislative and legal issues, and other relevant topics.

Currently, there is little information about how this type of education is being provided across the country. Much of the education that exists is being provided by consumer/survivor-run organizations. Some Protection and Advocacy (P&A) agencies (federally mandated organizations that exist in every state for the protection and advocacy of

people with disabilities) are providing (or contracting with other groups to provide) this education. The Center for Mental Health Services (as the result of consumer advocacy!) has asked the National Association of Protection and Advocacy Systems to encourage the state P&A organizations to make this type of education a priority.

- **Systems advocacy**

BACKGROUND:

Systems advocacy is a natural outgrowth of self-advocacy, and involves trying to effect positive change in the way services are developed and delivered in the “system” — the mental health system and/or other systems that directly affect one’s life and/or the lives of others.

There are many barriers to effective systems advocacy, including stigma, the lack of meaningful participation by consumers/survivors in the development of services and policies, and the lack of education about how systems work. Many systems are very resistant to change and funding is rarely provided for education in systems advocacy.

Systems advocacy education usually includes education about the mental health, legislative and legal systems. In addition, individuals are educated in public speaking, networking, letter writing, dealing with the media, research skills, and many other skills that are useful in making oneself heard and bringing about positive change. Education in advocacy skills *must be coupled* with ongoing supports to individuals who are involved in this work.

- **Meaningful consumer/survivor involvement on boards, committees, etc.**

BACKGROUND:

Over the last few years, new public policies and regulations have required consumer/survivor participation on mental health decision-making boards, councils and other governing and advisory groups. However, many times people are placed in those positions without the proper education to be effective. The lack of education along with

stigma often creates the perception that consumers/survivors really do not know what is good for themselves and cannot speak for themselves; consequently, consumers/survivors have to work hard to be respected and have their participation taken seriously. It is important that consumers/survivors become knowledgeable about the work of the board/committee they serve on and their responsibilities as members. Consumers/survivors should encourage the participation/appointment of other consumers/survivors, and work with other consumers/survivors on the board to develop consensus in advance on issues that are to be discussed at a meeting in order to present a loud and united voice.

Consumers/survivors must take an active role in getting themselves appointed to boards, councils and committees, because this is where decisions are made that affect services, resources and policies.

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FACILITATOR:

Yvette Sangster, an advocate and organizer for more than 15 years, is the founder and executive director of Advocacy Unlimited, Inc., in Wethersfield, Conn., a program owned and operated by people with psychiatric disabilities. Its primary mission is to educate people with psychiatric disabilities to be advocates who can, in turn, provide peer advocacy and educational workshops for consumers across the state. Yvette lectures and conducts workshops on consumer empowerment and advocacy, and has served on many boards, both in Connecticut and throughout the country.

CO-FACILITATOR:

Elizabeth Byers is the project coordinator and a founder of Project EQUALITY, a Salem, Oregon-based organization that works to ensure the availability of high-quality, equitable health care to Medicaid recipients and others. She is currently the organization's only staff, working with more than 300 volunteers. Previously the manager of a county-wide recycling program on the East Coast, Elizabeth came to her present position as a result of her experience as a Medicaid recipient following a serious stroke. She has also worked with the Oregon Health Action Campaign (OHAC).