

2. Organizing

- **Organizing a national voice**

ISSUE:

There is no national voice of mental health consumers and survivors, and little or no consistent representation of the grassroots movement in Washington. As a result, the movement has a limited impact on mental health policy at the national level.

BACKGROUND:

The self-help and advocacy movement of people with psychiatric histories began roughly 30 years ago, when former mental patients in several cities across the country began to organize groups with the common goals of fighting for patients' rights and against forced treatment, eradicating stigma, ending economic and social discrimination, and creating peer-run services as an alternative to the traditional mental health system. Many of the individuals who organized these early groups identified themselves as psychiatric survivors. They saw the mental health system as destructive and disempowering.

By 1980, individuals who considered themselves consumers of mental health services had begun to organize self-help/advocacy groups and peer-run services. While sharing many of the goals of the earlier movement groups, consumer groups did not seek to abolish the traditional mental health system, but to reform it.

Although there has been much progress in creating local and statewide grassroots organizing efforts to advocate for the rights of people diagnosed with psychiatric disabilities, to date we have failed to unify the movement so that we can be effective in national forums. In the past, one barrier to unity was ideological differences between those who call themselves consumers and those who call themselves survivors. However, in the more recent past there has been much more focus on commonalities than on differences, as movement activists united around such issues as outpatient commitment. Now, the chief obstacle can be more properly identified as territoriality: cooperation does not thrive where people are competing for funding.

- **Cross-disability organizing**

ISSUE:

The movement of people diagnosed with psychiatric disabilities would be more effective if we worked with activists in other disability rights movements toward goals that are important to all of us. Yet, as a rule, this does not happen.

BACKGROUND:

There is little coordination between the organizing efforts of mental health consumers/survivors and those of other disability groups, despite the fact that we may be working on the same issues. (For example, especially in rural areas, access to public transportation is a key issue for members of all disability groups.)

Often, there is a gap between people who want to engage in self-help and mutual support and those who want to work on an advocacy agenda. People may not be informed about important matters that will have an impact on their lives, such as the Work Incentives Act or the *Olmstead* decision, for example. We need better communication mechanisms to spread the cross-disability agenda.

- **Expanding the movement:
Organizing the unorganized**

ISSUE:

There are vast numbers of people diagnosed with mental illness who not only are not organized, but do not even know the movement exists. In order to increase the power of the movement, we need to expand our numbers.

BACKGROUND:

The problems are similar to those involved with cross-disability organizing. There must be better mechanisms established for communication, and leaders need to spread information about the issues to the grassroots. These leaders also need to communicate with state mental health and Medicaid officials (the latter because of managed care).

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FACILITATOR:

Ed Knight, Ph.D., is the CEO of the Mental Health Empowerment Project, Inc., which has helped start over 600 self-help groups for mental health recipients in New York State. He is a member of the executive committee of the Center for the Study of Issues in Public Mental Health and is an active researcher on self-help. He consults on rehabilitation, self-help and recovery throughout the country. Currently, he consults mainly with Options Mental Health in Colorado.

CO-FACILITATOR:

Howard Vogel, C.S.W., C.S.A.C., is executive director of Double Trouble in Recovery, Inc., in New York City, and deputy director of the Mental Health Empowerment Project, Inc. Previously, he worked as a substance abuse specialist and a social worker, and has consulted on mental health and substance abuse issues in New York and other states. He is currently a consultant to FHC Options-Colorado Health Network and the New York State Office of Mental Health, and serves on the MICA Task Force of the New York City Department of Mental Health, Mental Retardation and Alcoholism Services. He has made a variety of presentations on Double Trouble, a 12-step self-help group model for people with mental and substance abuse disorders, and on other mental health and substance abuse issues.