MAKING SELF HELP WORK

by Tanya Temkin, Carol Silverman, Ph.D. and Steven P. Segal, Ph.D.

In Philadelphia, a group of mental health consumers and other activists demonstrate at a state office building to demand housing for homeless people with mental disabilities. In response, the state agrees to commit several million dollars for long-term affordable housing.

On the West Coast, ex-patients with bipolar illness hold peer support groups and start an employment program to help members find and keep steady work.

In Vermont, parents of individuals with mental disabilities educate themselves and others about how to gain better control over their own lives.

These are all examples of what has been referred to as “empowerment.” But what does empowerment really mean? It’s the catch phrase of the 90’s, used by people in many disciplines, with many interests and diverse political leanings. Empowerment has at least as many meanings as there are people who use the term. Community psychologist Julian Rappaport probably says it best with a non-definition: “Empowerment is a little bit like obscenity; you have trouble defining it, but you know it when you see it.”

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Empowerment is certainly an often used term in human services. Yeheskel Hasenfeld, a professor of social work, defines it as “...a process through which clients obtain resources – personal, organizational, and community -- that, enable them to gain greater control over their environment and attain their aspirations.” And social worker Barbara Pinderhughes regards it as “...the capacity to influence the forces which

It isn’t a top-down process; a person with greater social influence can’t “empower” someone who is less advantaged. Mental health clients, who have been denied any real say about the services they get, or who don’t get a chance to pursue careers they want or to live in the housing of their choice, can’t be given power by even the most empathic mental health professionals.

Yet, as Pinderhughes and others have acknowledged, it isn’t a top-down process; a person with greater social influence can’t “empower” someone who is less advantaged. Mental health clients, who have been denied any real say about the services they get, or who don’t get a chance to pursue the careers they want or to live in the housing of their choice, can’t be given power by even the most empathic mental health professionals. And family members who are frustrated by the red tape of human service bureaucracies can’t be empowered by the providers who serve their loved ones. How can people who have systematically been denied power gain it?

What the organized efforts of both mental health clients and family members have shown us is, first, that they have achieved power through their own efforts. They typify the bottom-up process that is characteristic of real empowerment. They have organized, collectively, to get the informational and material resources they want, to gain credibility and clout for the organization they have formed, and to take on the arduous work of systems change. Note that key word – collectively. Empowerment is, above all, a dialectic process by which individuals become empowered through participation in a group effort, their groups gain power by entering the arena of community action, and the efforts of individuals and their groups make it possible for their communities to get resources and policy changes for their members.

What moves mental health clients and family members to get some measure of power? The impetus is much the same for both, although the content and emergent policy agendas may differ and sometimes even clash. Both direct recipients and family members have felt dissatisfaction with the mental health services they have
encountered, and both see a need to develop alternatives or to make the present service system accountable.

Both groups feel that there is a very special knowledge that comes from experiencing a situation directly – be it as an individual coping with a mental disability or as a loved one of a person struggling with debilitating emotional problems – and that people with this knowledge have something important to offer each other. Both also feel that there is something special about the support that comes from peers rather than professionals.

The authors in this issue discuss various ways empowerment emerges from the self-help process. In doing so, they touch on a number of interrelated issues on several levels. The first concerns the content of empowerment. For some, who are active in mental health self-help, empowerment means learning self-confidence and becoming able to cope successfully with a mental disability, either one’s own or that of a loved one. They seek to become active partners in treatment, and to collaborate with mental health providers in planning effective treatment strategies. In this issue, Sally Swope writes about how members of the Depressive and Manic Depressive Association support each others’ efforts in coping with stress, working with their therapists, and adhering to medication regimens. Donna Mayeux and Joyce Burland discuss Journey of Hope, a self-help program for families in which members help each other deal with feelings of being overwhelmed and isolated, and teach these coping skills to other family members.

For others, empowerment goes further, and also includes gaining more control over the material circumstances of one’s life, such as housing, income, and employment. An individual engaged in self help may gain the self-confidence to tangibly improve his or her living situation or to work more effectively with professional providers. Alternatively, current and former consumers may act as advocates for others with similar problems, offering peer-level help to link clients up with social services, SSI benefits, low-cost housing, and other resources to make this achievement possible. In “Who Said It Would Be Easy?”, Kathy Trevino speaks about how her own very personal experiences of homelessness and institutionalization inform her advocacy work on behalf of homeless mentally disabled clients, helping them deal with the concrete problems that undermine their stability. Marjorie Beggs describes how clients at self-help centers learn computer skills from other clients who have become computer experts, then use these skills and their newly gained self-confidence to get paying jobs.

The second issue relates to the context where empowerment is best developed. The benefits of self-help efforts focused on individual coping skills and gaining material resources are strengthened when participants get empowering roles in an organization or group. This could take place within autonomous self-help agencies such as the ones that are part of the Alameda County Network of Mental Health Clients where, as Sally Zinman and Vincent Hewitt describe, members make the rules, hold paid positions at all levels, take part in hiring decisions, and elect members of the board. Or, it could happen in mental health programs and public agencies where consumers achieve responsible positions, such as the position Wendy Walker-Davis holds as Consumer Relations Liaison in the California Department of Mental Health.

Organizations, too, can become empowered as they gain legitimacy and resources from the larger community. The article by Neal Brown and Jacqueline Parrish documents how consumer-survivors have successfully lobbied for federal resources for consumer-run organizations.

Finally, work has been directed beyond the individual and organizational level, regarding the empowerment of mental patients and their loved ones, as a class, as necessary for the empowerment of each. Here the focus is first on the political level – in directing legislation that governs the rights and opportunities afforded consumers and their families. The focus is also on general social transformations in changing the aspects of the larger culture that disempowers consumers and their families through blaming, stigmatization and the like.

Clearly, we have a long way to go before full empowerment is reached. However, the articles in this issue show how much has been accomplished by innovative, dedicated individuals and organizations. They also show that the process is rarely an easy one – and that setbacks may be inherent. Though, because of space limitations, we include articles from an extremely tiny percentage of the burgeoning mental health self-help community, we hope that the work of our contributors spurs others to undertake their own self-help efforts.