

History of the National Coalition of MH Consumer/Survivor Organizations

The National Coalition of Mental Health Consumer Survivor Organizations (NCMHCSO) was built on the foundation laid by the courageous work of those who started the mental health consumer/survivor movement in the early 1970's. Those early leaders were people with diagnoses of mental illness, who were inspired by people who were finding strength, courage and power by joining together to work for human and civil rights.

The visionary leaders of the consumer/survivor movement understood the only way to gain rights and independence was to come together and unite in a common cause. Meeting in churches, apartments and basements, we discovered the power of sharing our stories, of *being heard and of being understood*, instead of the idea that our labels defined us. We discovered we could shift into a vision of leading independent lives where we become authors rather than victims in our lives. As a result of the example of this early leadership hundreds of self-help groups, consumer-run initiatives, and statewide consumer organizations have been formed all over the country. These groups have had some success in influencing policy and practices on the local level. Despite this, we had, until two years ago, been unable to form a single, national organization, which could gain recognition and influence on a national level. In order to effect change on the grandest scale possible, we needed to have a united national consumer/survivor voice. Leaders of other national groups in Washington, D.C., elected officials, and the media have been searching for our united consumer voice. Without such a group to directly represent us, family groups or organizations of providers have been speaking for us. We have protested this trend to have other groups speak for us. We have proclaimed, "Nothing about us without us." Yet we had not organized ourselves into a common voice to carry out this goal, until now.

Today consumers and survivors are uniting nationally as never before. Our movement has gained the experience, wisdom and maturity to realize that it is time to see beyond our differences to the greater struggles urgently at hand. In May 2006, The National Empowerment Center (NEC) received a grant from the Public Welfare Foundation to organize a national consumer/survivor group. NEC began sponsoring a series of teleconferences with representatives of major consumer/survivor groups from a number of statewide, consumer-run organizations and three national federally funded Technical Assistance Centers (CONTAC, Self-help Clearinghouse, and NEC). This group crafted a mission, a statement of purpose and formed a ten-member Steering Committee, whose bios are on our website, www.ncmhcsso.org. The Steering Committee hired a Director of Public Policy, Lauren Spiro, who has office space in the Consumer Action Network of Washington, D.C. The Steering Committee developed a set of membership criteria, for admitting statewide consumer-run organizations or TA Centers:

1. The group is genuinely consumer/survivor run that is that the majority of the board and the staff are consumer/survivors.

2. The organization be involved with consumer/survivors statewide or in a significant region of their state and that the organizations agree to be in regular communication with their networks and ensure that they are inclusive and representative of their state.
3. The organization's board approve in writing the mission and statement of purpose of the coalition.
4. That the organization agrees to work out differences among themselves and any other member organizations in a collaborative fashion.
5. The organization advocate that the voice of consumer/survivors be central to decision making at all levels.

Presently there are 36 member organizations (32 states and 4 national TA Centers). The member states consist of all the states with greater than five million people except Illinois. Efforts are underway by the Coalition and the TA Centers to organize statewide consumer organizations in the other 18 states not yet represented.

We have conducted two annual face-to-face meetings. The most recent was held in October 2007, in St. Louis, MO. There were 130 consumer/survivor participants. We used the meeting to develop a set of policy initiatives for the coming year. We have found the common ground that unites us rather than those issues that divide us. This coalition provides the vehicle for having a united consumer/survivor voice that can impact decisions on policy, regulation, evaluation, training, funding, services and more.

Already the Coalition has played a role in reversing the cuts by the present administration to many consumer-run initiatives. It has increased its effectiveness by working in partnership with other organizations such as the Bazelon Center for Mental Health Law, the American Association of Persons with Disabilities, and the Campaign for Mental Health Reform.