

National Coalition of Mental Health Consumer/Survivor Organizations July 10, 2006 Teleconference Notes

Mission Statement

The National Coalition of Mental Health Consumer/Survivor Organizations (NCMHCSO), will ensure that consumer/survivors have a major voice in the development and implementation of healthcare, mental health, and social policies at the local, state, and national levels empowering people to recover a full life in the community.

Participating:

Judene Shelley and Dan Fisher, National Empowerment Center, MA
Joseph Rogers, National Self-Help Clearinghouse, PA
Sherry Jenkins Tucker, GA MH Consumer Network
Peter Ashenden, Mental Health Empowerment Project
Michele D. Curran and Sally Zinman, CA Network of Mental Health Clients
Jack Bucher, Collaborative Support Programs of NJ Inc.
Dave Woledge, PA MH Consumer's Association
Mary Blake, Effie Smith, Consumer Action Network (CAN), DC
Doug DeVoe, Ohio Advocates for Mental Health
Amy Smith, WE CAN! of Colorado
Patrick Hendry, Florida Peer Network
Kay Rote, Oklahoma Mental Health Consumer Council
Lauren Spiro, VOCAL (Virginia Organization of Consumers Asserting Leadership)
Darby Penney, Community Consortium, NY
Chris Busby, Transformation Center, MA
Fred Fay, Justice for All, Concord, MA, Consultant
Annette Deonorine, Advocacy Unlimited, CT
Mike Finkle, On Our Own of MD
Kay Rote, Oklahoma MH Consumer Council
Carole Glover, Denver Nobles, Meaningful Minds of Louisiana
Joleen Smith, Texas MH Consumers
Andrew Phelps, NO List, CA
Doreen Mills, Kentucky Consumer Advocate Network

1. Report from the Name and Mission Statement Committee

The name has been agreed upon:

National Coalition of Mental Health Consumer/Survivor Organizations.

The mission statement was agreed upon with one change of the word enabling to empowering. (listed above)

Statement of Purpose. The committee will submit to the group by email. The group will vote it either up or down. It was suggested that the email indicate clearly in the subject line: "official vote on mission statement."

DRAFT OF STATEMENT OF PURPOSE

Mental health consumers/survivors are leading the transformation of the mental health field through our authentic voice and vision for self-directed recovery. Our vision of recovery goes far beyond treatment, because it is about *all* the elements that go into good lives—housing, education, jobs, social relationships, and full participation in the community. Our vision was echoed in the New Freedom Commission Report, which sees a “future when everyone with mental illness will recover.”

Our national coalition of organizations representing people who are recovering or have recovered proposes a new consensus for the mental health field:

- **Recovery:** Recovery is real and possible for everyone. To recover, we need services and supports that treat us with dignity, respect our rights, allow us to make choices, and provide assistance with our real-life, self-defined needs. This range of services must include consumer-run and operated programs.
- **Self Determination:** Self-determination is essential for recovery to occur. We need to be in control of our own lives.
- **Holistic Choices:** We need choices that meet our self-defined needs. We need a wide range of recovery-oriented services and supports to assist us in achieving our goals. These include not only medical and psychosocial services, but also assistance with housing, education, and career development, all of which can be consumer-run. We need these opportunities to achieve full integration into the community.

Voice: We must have a voice in our recovery and in the policies facilitating our recovery. We are the most authentic voice in the mental health system, since mental health decisions affect every aspect of our lives. We bring our *lived experience*, therefore, we must be central in any dialogues and decisions about mental health issues at all levels. This is empowerment.

Personhood: We are whole human beings and will campaign to remove stigma and discrimination. We are no more violent than the general population and have the ability to make our own decisions. We have the same dreams as all members of the community. A barrier-free community is one free from discrimination and stigma.

We support the consensus statement on recovery endorsed by the Federal mental health agency, SAMHSA (www.mentalhealth.samhsa.gov). In the emerging field of “evidence based practice,” we know from our full range of lived experiences what works *because WE ARE THE EVIDENCE!*

2. Membership Committee Report

The members of the membership committee met and elected a Chair - Peter Ashenden, a Recording Secretary - Debra LaVergne, and Judene Shelley will be helping with logistical duties. Other members of the committee are Jack Bucher, Regina Koch-Mart and Ann Rider.

The membership committee agreed on the importance of assuring that organizations have communication with consumer/survivor/expatients in their area. The membership committee felt that statewide or regional groups with demonstrated access to consumer/survivor/expatients in that area should be included. Each group needs to indicate that they are in contact with c/s/x in a demonstrated way. Joseph said that there

were at least 20 groups in PA that could qualify under that definition. This will be discussed further by the Steering Committee.

The Membership Committee is developing an application form would be used by all including the organizations that are already part of the Coalition, assuring that their Boards of Directors are in agreement.

Fred Fay joined the call as a Consultant. Fred has been involved with beginning three disability rights organizations. When the American Coalition of Citizens with Disabilities (ACCD) was organized, some wanted to include national organizations; others wanted just state; others wanted individual. It was set up that the national organizations would each get 10 votes, state 3 votes, and individuals 1 vote. Fred felt that the awkward organizational structural contributed to ACCD's demise. Joseph said that NMHA is struggling with a three-tier membership that is creating massive confusion. He felt that simplicity would be best. We may want a simple solution given major barriers other organizations have had in past in deciding membership levels. To be either a state organization or demonstrate that you are representing your state is the simplest model. It was suggested that now the group look at initial membership and then that group could take a while to decide on the next tier of membership. The Steering Committee and Membership Committee will continue to explore the issues of whether we are opening the Coalition to (small) area groups and other national groups. We want to be as inclusive as possible.

Jack Bucher said that the Membership Committee is planning to reach out to states that don't have representation. The Coalition will also reach out to assist states that do not have a statewide organization to develop and grow one.

3. Report of the Hiring Committee for Position in DC

So far 12 people have applied for the position in DC. After some discussion including the fact that numerous people did not get the job announcement, the application deadline will be extended one week to July 17th. The job announcement will be sent out broadly.

4. Governance of the Coalition

Dan introduced his mentor, Fred Fay, a leader in the disability movement and a psychiatric survivor. Fred has helped organize 3 national groups and many local groups. Fred can share his wealth of experience and has offered to consult to the formation of our group.

Fred Fay: quoting Margaret Mead, "Never doubt that a small group of concerned citizens can change the world, indeed it is the only thing that ever has."

Fred has been involved in starting three national organizations. He would suggest the American Association of People with Disabilities (AAPD) as a model. AAPD has by-laws with a self-selecting Board of Directors and a much smaller steering committee. They would have preferred to include a national Psychiatric survivor group when we started these organizations.

Justin Dart, a national disability leader, used to say: "Vote as if your life depended on it, it does." Fred adds: "Organize as if your life depended upon it, it does. Conceive,

believe and achieve. You have clearly conceived a national organization, In the coming months you will achieve a national coalition...”

Sally Zinman presented the model of the CA Network of Mental Health Clients. They have a 15-member board with a mechanism to represent the diversity of the state. Every committee has representation from each region of the state. Decisions are made by majority vote, yet most are made by consensus. Sally said that CNMHC has avoided very divisive issues, and have taken more mainstream issues.

For now, the National Coalition will continue to gather examples of different types of governance. Joseph said that the European Users Federation is an interesting model.

It was observed that in the past we have had difficulty trusting and having a representative body that we are comfortable is representing us.

The group discussed whether other groups should be represented on the Steering Committee. The Steering Committee is an interim operational organization. Carole Glover and Effie Smith volunteered to be on the Steering Committee to bring a cultural perspective to the committee that is not already represented. In addition, they are representatives of statewide groups. The group decided they will join the Steering Committee.

5. Action Agenda

The Coalition would like to have an action agenda instead of a reactive posture. What are the issues we want to prioritize? The following is a starter list of topics suggested by people:

1. Reestablish the equity of the consumer/survivor statewide networking grants with the family statewide grants by restoring their full funding.
2. Ensure reauthorization of SAMHSA.
3. End the direct advertising by drug companies to the public, or ensure equal time for other points of view, i.e. non-medical description of our issues: such as requiring equal time devoted to people telling their stories of recovery. Independent, unbiased information about medications based on non-pharmaceutical company information.
4. Advocate for recovery information and stories in every educational setting receiving state or federal funding.
5. Voter registration for people labeled with mental illness wherever we reside.
6. Promote mandatory consumer-run recovery evaluation teams in every service receiving Federal funding to assess the degree to which those services are recovery-oriented.

Other Action Agenda ideas discussed:

1. The Mental Health Block Grants. Denver Nobles added looking at how the Block Grant dollars are being spent. They are supposed to have significant support for consumer organizations or consumer activities. A discussion followed about how

effective consumers are on the Planning Councils. There is a national organization of state mental health planning councils, headquartered at NMHA, that can give TA to help educate people about the statute and their role. Joseph will forward the contact information to everyone.

Sherry Jenkins Tucker of Georgia said that she just had a Planning Council meeting today. They talked about the transformation language that is proposed, yet hasn't been finalized. They would like to see the priorities move towards transformation that would afford more opportunities for consumer organizations and peer work.

Joseph and Dan will try to meet with Katherine Power in August regarding the Block Grants.

2. Advocating for consumer/survivor representation at selected national meetings such as NASMHPD. Kay Rote offered to write a letter with Joseph who was the only consumer at some of the NASMHPD meetings taking place now.

Kay is also chairing the Fundraising and Development Committee and is looking for additional ideas and members.

6. The following Agenda items were not discussed due to lack of time:

A. Announcing the birth of the Coalition: in print, brochure, logo, on internet, in DC by event, starting a website, NY regional meeting in September.

B. Face-to-face meeting of Coalition in Oct. at Alternatives, caucus, and a room in a nearby restaurant.

7. The next meeting was scheduled for Monday, August 7, 2006 at 3:30 p.m. EST. The first Monday of the month time will be continued.