

**National Coalition of Mental Health Consumer/Survivor Organizations**  
**September 14, 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 and lead a full life in the community.

**Participating:**

Dan Fisher and Judene Shelley, National Empowerment Center, MA  
Lauren Spiro, Director of Public Policy  
Ann Benner, VOCAL, VA  
Isaac Brown, Mental Health Empowerment Project, NY  
Dennis Budd, Kansas Consumer AC  
Chris Busby, M-POWER, The Transformation Center, MA  
Linda Corey, Vermont Psychiatric Survivors  
Mike Finkle, On Our Own of MD  
Carole Glover, Meaningful Minds of Louisiana  
Patrick Hendry, Florida MH Network  
Doreen Mills, Kentucky Consumer Advocates Network (KCAN)  
Bonnie Pate, South Carolina Share  
Andrew Phelps, NO List, CA  
Dave Sanders, W VA MH Consumer's Association  
Amy Smith, WE CAN! of Colorado  
Effie Smith, Consumer Action Network (CAN), DC  
Joleen Smith, Texas MH Consumers  
Sherry Jenkins Tucker, Georgia MH Consumer Network  
Dave Woledge and Mary Kohut, Pennsylvania MH Consumer Association

The press release announcing the formation of the Coalition was released on Sept. 6, 2006. We have received many phone calls and emails expressing interest in the Coalition and congratulating all of us on its formation.

**1. Membership**

The Membership Committee has sent the final membership application form to the list and it is posted at the website: [www.ncmhcsso.org](http://www.ncmhcsso.org). The Membership Committee is keeping open the possibility that there would be more than one organization from each state participating in the coalition. Several people said that being inclusive was "a smart move." All applications received will be reviewed by the Membership Committee. The applications recommended for membership will be sent on to the Steering Committee. All of the organizations participating in these teleconferences are encouraged to get their applications in by September 29, 2006 for the first review. Every organization needs to send in a membership application.

The application form includes the requirements for membership including:

- A. Statewide or representing some significant region of a state.
- B. Run by consumer/survivors. A consumer-run organization has consumers in the majority on both its board and staff (when organization has staff).
- C. Agreement with the values in the Coalition's Mission Statement, Statement of Purpose, and Principle of Respect (on reverse side of membership application)
- D. Willingness to participate in Coalition activities.

2. **Portland Event-** Oct 26, 2006 from 6 to 9 p.m.- Strengthening Our Voice. Space is limited to 130 people. We will have fun, food and music. The Steering Committee and staff will talk about NCMHCSO and hear from organizations about how we can work together. Each organization that has been part of this process may send up to two people; please RSVP. If there is additional space, we can add people later.

### 3. **Activities of Director**

Lauren Spiro was introduced as the Coalition's Director of Public Policy. Her upcoming activities include:

A. Formation of DC Advisory Committee. On September 25, 2006 we are sponsoring a dinner and organizational meeting for the DC Committee.

B. Mental Health Policy Roundtable sponsored by NAMHSPD (National Association of State Mental Health Program Directors), Sept 19, 2006 at Bazelon Center for Mental Health Law. Lauren is co-presenting with Paolo del Vecchio (Consumer Affairs Specialist, Center for Mental Health Services, Substance Abuse and Mental Health Services Administration) on the topic of the National Consensus Statement on Mental Health Recovery.

C. Brief talk on NCMHCSO at the National Coalition on Mental Health and Aging meeting on Sept 22, 2006. The representatives on the teleconference told Lauren about the programs in their states for older people.

D. Lauren is starting to network, meeting people, talking about the coalition, and getting some visibility.

E. Lauren attended a dinner with the Red Cross September 8, 2006 on the topic of Peer Support in Times of Disaster. The Red Cross leaders seemed receptive to including peers in future relief efforts. This is a big move for the Red Cross. This linking would happen with Red Cross state chapters working with local consumer organizations.

### 4. **Fundraising Committee**

The Public Welfare Foundation grant will probably last for a year and a half. At some time there will need to be some fee or membership dues. It is usual and customary to have a fee schedule based on budgets. Funding organizations look favorably when there are some membership dues.

Mike Finkle recommended looking at USFRA fees that are based on what an organization's annual budget is. USFRA's schedule for membership ranges from \$170 for organizations with below \$100,000 annual operating budget to \$1,230 for organizations with \$1 million to \$2 million annual operating budget (and it goes up from there). The coalition might have the lowest amount even lower than that. If an organization lost funding, the fee would be adjustable every year.

Dan received a "willingness to talk" about possible funding from the MacArthur Foundation. In the past they've been reluctant to fund any consumer group as they didn't know which one to fund and didn't want to leave some out. Dave Sanders sent information previously on some possible foundations. Kay Rote, chair of the fundraising committee, was not on the teleconference so the discussion will be continued later.

5. **Priorities:** Topics of concern on a national level so we may begin formulating our action agenda. This can be effectively done by:

- A. Gathering topics from members
- B. Prioritizing the topics
- C. Coming up with goals, steps, timetable, and people to carry out the agenda items
- D. Feedback on the progress towards the goals

The group discussed and agreed upon the following six priorities.

- 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 – ongoing and long-term.
- 3) Develop Peer Support in Disaster Planning at state level and with Red Cross Chapters.
- 4) Advocate for recovery information and stories in every educational setting receiving state or federal funding.

- 5) Voter registration for consumer/survivors 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.

It was suggested that next year we do a survey of our membership to gather some information about the services of the organizations in the coalition and specific topics such as what states are doing around aging adults and youth in transition.

6. **DC Event:** Begin planning for a DC event announcing and celebrating the National Coalition. This would be an opportunity to partner with other organizations in DC. We could put our priorities on the table on Capitol Hill. Effie Smith said that a good place for the event might be the True Reformer Building on U Street. A planning group could help plan this event, including food, possible co-sponsors, etc.

7. The next meeting of the National Coalition will be on October 26, in Portland, Oregon. We will get to see each other face to face.