

National Coalition of Mental Health Consumer/Survivor Organizations
October 26, 2006, Portland, Oregon
Notes From Our First In Person (Face-to-Face) Organizational Meeting

The room was filled to capacity - 130 consumer/survivors from across the country gathered to continue organizing our national voice. This was a time of great celebration and anticipation. We are putting old differences aside and coming together in a new spirit of cooperation to form our own genuine voice. We declared that our movement rallies behind the principle of nothing about us without us.

After music, pizza, salad, greeting one another and socializing, the town meeting style gathering began. Everyone received a handout of information on the coalition to date, such as the mission, statement of purpose, website, and a membership application. We had a circular seating pattern, with seven members of the steering committee or their alternates (Dan Fisher, Joseph Rogers, Sally Zinman, Mary Blake, Emily Hoffman, Doug DeVoe, and Jane Winterling) and our newly hired director of Public Policy, Lauren Spiro introducing themselves.

Dan Fisher gave a summary of our progress in organizing in the last six months. Though there have been several attempts to form a national voice of consumer/survivors over the last 20 years, the conditions seem most favorable now. We as a people are realizing that our need to organize outweighs our need to assert our individual differences. The constant threats to the SAMHSA funding of 19 statewide consumer/survivor groups, Alternatives Conferences, and TA centers have to be countered. There is a threat to the very existence of SAMHSA. There is a need to ensure that the recommendations of the New Freedom Commission on Mental Health Report (www.mentalhealthcommission.gov) for a transformation to a recovery-based, consumer-driven system are carried out. There has been the growth of a number of strong statewide organizations.

The current building of trust among consumer/survivor leaders enables a new cooperation. Dan described that in May, the National Empowerment Center (NEC) obtained a grant from the Public Welfare Foundation for the purpose of organizing a national coalition. (The early history of the Coalition is on this website). The purpose of the meeting was to report on progress to date, to introduce the Steering Committee and Lauren Spiro, and especially to gain feedback from the gathered representatives to help guide the further formation of the Coalition. Each of the Steering Committee members then gave a brief talk on what they would like to see this Coalition become.

- Joseph Rogers said that this new era of organizing our voice began with the cooperation our community displayed in ensuring that our voice would be heard in the New Freedom Commission Report. He hoped that this group could incorporate the National Platform developed at the National Summit of Consumer/Survivors held in Portland in the 90's.
- Sally Zinman said that she sees a driving need to have a national voice. "Other groups are speaking for us. We have to influence national policy in the same way States with strong consumer/survivor voices influence their State's policy. For

this overarching mission, we need to put our differences aside. There is a need to reach compromises. In fact, we really do share similar goals and values throughout the country.”

- Emily Hoffman summarized her experience of being a token consumer/survivor in Washington. She cited the slights and exclusions she endured because she was working without an umbrella organization.
- Jane Winterling appealed to us to create a new culture of shared responsibility, which encourages everyone to play a role in leadership. This decreases the over reliance on a few individuals who often end up either burned out or fired.
- Lauren Spiro said that she is delighted to serve as the Coalition’s person in Washington, D.C. She spoke about it being an exciting time to be a consumer/survivor in America and to be part of the explosive growth of innovative projects, consortiums and initiatives that are spreading around the country. In the few weeks she had been on the job she had a number of meetings with consumer/survivor advocates as well as policymakers. She has been impressed and humbled by the enthusiastic welcome of our existence in the nations capitol. A number of organizations have waited a long time for this day – a day when we speak with a united voice and have an official presence in Washington. She has had discussions with some of our key organization allies, including cross-disability organizations all of whom look forward to working with us to advance our shared agendas and legislative priorities. She emphasized the importance of us continuing to stand strong, to stand together and to support one another as we transform our healthcare system.
- Mary Blake described how her organization, the Consumer Action Network has been giving voice to consumer/survivors in DC. Their organization has also agreed to donate office and meeting space to the Coalition.
- Doug DeVoe warned of the elephant in the room, the pharmaceutical industry. It clearly has been the dominant force in national mental health policy. We need to counter its influence.

Then came the most exciting part of the meeting. Dan asked “What would you like to see the National Coalition do for you?” The spirited participation by many members of the gathering was electric. Susan Rogers kept track of peoples’ suggestions, which are listed below. The topics covered the entire range of issues we face from housing, to the need for our rights to be recognized, to the need to be as democratic as possible while getting work done. People want to get the word out that recovery is real, and many felt that telling our stories is a critical way to do this. There were concerns that the group be as diverse as possible. Also people wanted us to advocate for trauma informed services to take the place of traumatic services.

There was concern about membership. How could we be as inclusive as possible? The Steering Committee explained that it is starting by organizing statewide organizations. This step of organizing the organized is merely a first step however, not the final product. There were concerns that the Coalition be as representative of people of color as possible. There also was a concern that there be as much transparency on the organizing efforts as possible. The Steering Committee thanked Mike Hlebechuk and

Judene Shelley for the meeting preparations which ensured that the evening was a success.

The following were suggestions from the meeting participants. Although they were suggested in random order, they have been grouped by theme.

PHILOSOPHY

- Keep our history alive.
- Remember that we are a civil rights movement.
- Fight for respect.
- Promote inclusion.
- Make cultural competence a priority.
- Our credibility must grow from the grassroots.
- We must build moral leadership.

ORGANIZATIONAL STRUCTURE

- Membership should be open not just to state organizations but to individuals.
- Promote applications to the Coalition.
- Reach out to entities representing children and families.
- Spread the leadership.
- Establish an Accountability Task Force:
 - Service providers must be held accountable for doing what they should.
- Do outreach to people-of-color organization(s).
- Promote the representation of youth in the movement and the Coalition.

ORGANIZATIONAL METHODS

- Help people form state organizations.
- Seek consensus and find issues that unite us.
 - Avoid infighting.
- Provide consistent information, clear messages, and transparent agendas.
- Create a blog on the Coalition Web site to keep constituents abreast of developments.
 - Include a comment option.
- Rally around one issue at a time: e.g., “Recovery happens.”
 - Take it to the schools and other community venues.
- Take advantage of buying power.
- Focus on resources:
 - Raise funds to support advocacy.
 - Work collaboratively to seek funding for peer support.
- Promote cross-disability organizing.

ISSUES TO ADDRESS (TACKLE TOUGH ISSUES):

- Address universal screening leading to labeling.
- Address crisis in police shooting of consumers/survivors/ex-patients.
- Take a strong stand against seclusion and restraint and involuntary outpatient commitment.

- Promote simplification of back-to-work incentives.
- Promote people-first language.
- Address the issue of people labeled with mental illness in jails and prisons.
- Address trauma issues:
 - Push for an end to child abuse and trauma.
 - Promote trauma recovery services.
- Address homelessness:
 - Promote housing.
- Address employment.
- Promote research into best practices.
- Promote a holistic health/life outlook:
 - Promote the establishment of “wellness centers” and let people know they exist.

POLICY DEVELOPMENT

- Review the planks developed at the first National Summit of Mental Health Consumers and Survivors for policy guidance.
- Establish a process to decide on policy (e.g., the plank process).
- Develop position statements at the grassroots/state level on such topics as:
 - Housing
 - Employment
 - Seclusion and restraint
 - Involuntary outpatient commitment, etc.
- Contact the Maryland lobbying group, Community Behavioral Health Association of Maryland.

PUBLIC ACTION AND PUBLIC RELATIONS

- Employ non-violent direct action (civil disobedience).
- March on Capitol Hill.
- File class-action suits.
- Create documentaries showing movement history and progress.
- Create a memorial in Washington, D.C., that would include the names of deceased consumers/survivors/ex-patients.
- Educate the public by telling stories of trauma survivors.
- Differentiate NCMHCSO from the national technical assistance centers.
- Create an “education arm” to activate our network.