

## National Coalition Annual Meeting Report - 2009

On October 29, 2009 The National Coalition of Mental Health Consumer/Survivor Organizations (NCMHCSO) held its 4<sup>th</sup> annual meeting in Omaha, Nebraska. Over 125 people were in attendance from across the US. The meeting opened with an opportunity for people to network by six national regions, as was requested in Coalition member conference calls.

Following the networking portion of the meeting, Lauren Spiro announced the Judi Chamberlin "Joy in Advocacy" Award. Steering Committee members Sally Zinman, Joe Rogers, and Dan Fisher read moving tributes to Judi's incredible history of advocacy and activism.

NCMHCSO Director Lauren Spiro talked about the Coalition's progress in Washington. Coalition staff participated in a several White House briefings and policy meetings with senior advisors to the President, and we were present for President Obama's invitation-only historic signing of the commitment to sign the UN Convention on the Rights of Persons with Disabilities.

New Membership Levels were announced and discussed. There are 31 statewide members today. New categories include:

- a. Associate members (incorporated, consumer-run groups that are not statewide organizations)
- b. Supporter Member – Group (non-incorporated groups; WRAP groups, support groups)
- c. Supporter Member – Individual
- d. "Friend" level – non-consumer run organizations who support the mission/vision

The Coalition accomplishments were listed. One of the highlights: In March 2009, Congress signed into law \$960,000 to increase funding for consumer statewide networks, which will allow 12 additional consumer-run networks to receive grants in the amount of \$70,000 per year for 3 years. [For a complete list of 2009 accomplishments, click here.](#)

Lauren introduced Emotional CPR (eCPR) which will be a Coalition project. There will be a two-day certification next year; a train-the-trainers offered in 2011. We envision eCPR as a micro-enterprise for people, as well as a way of providing a peer-centered model of approaching emotional distress and crisis.

The Statewide Consumer Network (SCNs) grantees announced themselves. It's our collective accomplishment. No one else was advocating for increased funding to these SCNs.

Director of Federal Relations Tom Bryant introduced himself and gave an orientation to policy. Tom has worked with the Carter Center to include more

consumers in their conferences; and to get more consumer/survivor representation on the Mental Health Task Force.

He has spent most of his time focusing on health care reform, and gave an update on the progress of the legislation. He believes that the reform will result in a step in the right direction; mental health will fare well.

Another key policy issue is re-authorization of SAMHSA, which won't happen until health care reform is done. Patrick Kennedy will be leading that. He is our close friend on the Hill and very attuned to consumer input and interest.

Tom wants to organize pressure groups – lobbying to email their Congresspeople. The goal is to increase the role of MH consumers on the Hill. The more we can have a structured organizational response, the better we will be known. The more members and supporters we have, the more influence we will have on the Hill. He noted that other disability organizations are our best allies on the Hill.

Dan Fisher, National Coalition Steering Committee member, gave a history of the Justice for all Action Network (JFAAN), a national coalition seeking to bring together leaders of organizations run by people with disabilities. The JFAAN steering committee is only made up of groups run by people with disabilities. The mission and vision is very similar to our own: self-determination, etc.

Leaders are needed on the state level to be a part of JFAAN cross disability coalitions at the state level; organized by people with disabilities. Please sign up or email [info@ncmhcs.org](mailto:info@ncmhcs.org) if you are interested in participating.

The Coalition met with Cindy Mann, the new director of the CMS Medicaid Division requesting 6 reforms in Medicaid to implement recovery:

1. Supervision of Peer specialists by other peers
2. Peers as Personal Care Attendants for consumers
3. Self-determination Care Accounts
4. Expand medical necessity to include community integration
5. Peers can play a central role in evaluation of services
6. Ensure significant participation by mental health peers on the state Medicaid Advisory Councils:

Medicaid advisory councils were discussed. There is a Federal requirement that they have people with disabilities on these councils, yet often that requirement is not adhered to. Please check back at the website for information about how to join the Medicaid Advisory Council in your state.

Those in attendance gave feedback on the policy priorities for the coming year. There is a need for a National Recovery and Wellbeing initiative or some kind of legislation. In the developmental disabilities community they have overarching legislation. We don't have one for systems change.

The importance of social security reform was discussed; need for Medicaid buy-in; the need for Medicaid to fund more in the way of community supports. Right now the system is too complicated (waivers, etc). It needs to be more user-friendly.

Another need cited was for consumer/survivor representation on the federal agencies that affect us. SAMHSA is currently the only agency that has consumers on its advisory board.

We need to promote stronger policies about hiring consumers through the MH system not just as peer counselors. We need to establish a percentage for number critical mass to transform - 25%?

Margaret Hamburg is the new FDA commissioner. She has stated intent to change the Big Pharma influence on the FDA. We need to connect with her and work for reform of the FDA.

Leah Harris gave a short update on social networking, including the Coalition's Facebook cause and group pages, as well as the growing number of consumer/survivor activists who are connecting on Facebook as well as other social networking sites.

Steering Committee member Sally Zinman talked about the dramatic changes she has seen in rights, protections, consumer run services – indicative of the past, future. While it can be frustrating when change doesn't seem to happen as fast as we would like, she has seen incredible change in the 35 years she has been an activist.