

## **National Coalition for Mental Health Recovery provides consumer/survivor input to NIMH - July 27 and 28th, 2011**

Daniel Fisher was invited to speak at the 2011 NIMH Services Research Conference on the topic: "What research do Mental Health Consumers want carried out?" In preparation for the conference he surveyed the members of the Coalition and compiled a set of 12 research priorities (listed below).

On July 27, Dan presented these priorities to the NIMH Services Research Conference. In addition to the priorities, he summarized his own recovery and the history of the consumer/survivor movement. He also emphasized the importance of approaching the research of persons with lived experience of mental health issues with great delicacy and sensitivity. He pointed out that we have been traumatized prior to and during treatment. This has made it difficult for us to trust experts or others in positions of authority. Community-based participatory research offers hope as a new, trauma-informed research process. He also pointed to the need for engaging consumers in meaningful dialogue about research priorities.

On July 28, Dan and Lauren Spiro, Director of the National Coalition for Mental Health Recovery, met with Dr. Thomas Insel, Director of NIMH, and Robert Heinson, Director of Services Research Branch of NIMH. They shared about their own recovery, and emphasized the importance of consumer involvement in all aspects of NIMH research. They pointed to the need to shift the NIMH priorities from biological research to holistic research. They debated Dr. Insel on the question of "cure" versus "recovery." Dr. Insel's position on recovery is that advocates should not settle for mere recovery. He contends that they should continue to press for cures to mental illness.

Many people with lived experience on the other hand, contend that these are not illnesses just like any other. In fact, their view is that all people have varying degrees of mental diversity and trauma. In certain situations, the trauma and diversity interfere with the person's capacity to form the peer relationships and create meaningful lives, which fulfill their deeper selves. Many people have found recovery through building and participating in communities and relationships.

Despite these differences in world view, the meeting was respectfully carried out in the spirit of genuine dialogue. Dr. Insel invited the NCMHR to become a member of the Alliance for Research Progress, a multi-stakeholder group designed to provide input to NIMH. Dr. Insel also showed an interest in the Open Dialogue approach from Finland. He said that their Global Mental Health Division, headed by Pamela Collins, was exploring the ways that developing countries have been approaching mental health problems with fewer resources.

The following are the research priorities submitted to NIMH:

## **How to engage the consumer/survivor community in setting NIMH research priorities and process**

Mental health consumers/survivors want to play a meaningful role in setting the research priorities of the NIMH: they want to be involved in selection of topics, in research design, in peer review, and in research evaluation and dissemination. By partnering with the consumer/survivor community, NIMH services research will be more relevant, the findings will be more likely to be disseminated, and will have a broader base of support

### **Ways that consumer/survivors want to be involved in NIMH funded research**

- NIMH should establish a consumer/survivor advisory committee, consisting of c/s leaders who represent the breadth of our community, which could work closely with the SAMHSA consumer/survivor advisory committee to collaboratively set research priorities for NIMH
- Priority be given to Participatory Action Research and mixed qualitative methods that value the cultural and social dimensions of research as much as the biological; In a world calling for evidence-based practice, researchers need to consult C/S community because we are the evidence

### **Research Priorities of Consumer Community (based on a survey of national c/s leaders)**

1. Impact of wellness dimensions such as diet, exercise, meditation, stress reduction, social supports, emotional intelligence on MH
2. To what degree is the increase in mortality among persons with severe mental health issues due to psychiatric medications?
3. Self-determination budgeting, within self-determination culture change: to what degree do people recover when they have their own money and can directly control treatment decisions
4. Peer-run respites: outcomes especially as far as recovery and wellness
5. Further delineation of the factors most important in recovery
6. What are the best parameters for measuring recovery from severe mental health issues: hope, purpose in life, empowerment, social connections etc.
7. Are people trained in Emotional CPR (eCPR) better able to help others through an emotional crisis? Can training in eCPR reduce the number of negative interactions with law enforcement?

8. Open Dialogue as a way to reduce hospitalization and medication in persons with first break psychosis
9. Research on trauma: its impact on mental health; harm/trauma/negative effects of coercive treatment; degree to which peers can assist in healing trauma
10. Collection of outcomes data on a national and state level; outcomes need to be based on recovery and wellness; also widespread use of the Recovery Oriented Service Indicators (ROSI) to measure the degree to which services are recovery-oriented
11. To what degree do ACOs(Accountable Care Organizations) and health homes under the Affordable Care Act improve recovery and wellness?
12. How do consumers transition from mental health system programs to natural supports in the community? How can peers facilitate the building of a social network for a person who mainly relies on providers for support? Is there a difference in the capacity of peers hired by the system and peers working for a peer-run organization to help persons build natural supports?