

National Coalition for Mental Health Recovery

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

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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?