National Coalition for Mental Health Recovery
2759 Martin Luther King, Jr. Avenue, SE Suite 201
Washington, D. C. 20032

July 2, 2013

Dear President Obama:

We congratulate you and your administration on your efforts to bring mental health conditions "out of the shadows," as you said at the White House Conference on Mental Health on June 3. This is a golden opportunity to initiate a truly national dialogue on the important mental health issues facing our nation. We, a national coalition of people with first-hand experience of the mental health system who are in recovery and provide support to others facing similar issues in communities across the country, are eager to be meaningfully involved in these dialogues.

We also want to share our reactions to the White House Conference, in hopes that the dialogues will be truly inclusive of those of us who are experts by experience.

First, we were very disappointed that so few individuals who identify as having "lived experience" of mental health issues and treatment were invited. For most other issues related to health and social change, people who represent the populations and issues under discussion – including members of racial and ethnic minority communities and persons with physical and developmental disabilities – would be well represented so that all the conference participants could benefit from their knowledge, expertise, and understanding of the impact of policy changes on their lives and the lives of fellow community members.

In addition, only one of the approximately 15 speakers publicly acknowledged having lived experience; however, she identified more as a family member – and her role was primarily to introduce you. Our organization would like to communicate to you and your administration a perspective on the difference between a person with lived experience and a family member. This is an important distinction – and one that does not degrade the importance of family. Both perspectives should be considered by your administration in your efforts to reform our nation's mental health care system.

There was also a lack of emphasis on recovery and wellness. The conference could have benefited from more recovery-oriented presentations, such as the presentation about MTV's *Love Is Louder,*[1] involving individuals telling their recovery stories. While the increased access to care that will be provided by the Affordable Care Act (ACA) and parity legislation (when your administration issues the final regulations)

was described, the shortage of providers was also acknowledged. This is another area in which we can offer our expertise and that of our members. Peer support, which the Substance Abuse and Mental Health Services Administration (SAMHSA, 2006) has identified as a vital component in recovery, has a long history in our community and others (such as the substance abuse recovery community). Peer-run services are based on the principle that individuals who have shared similar experiences can help themselves and each other. There is both a growing evidence base for these supports and an increasingly trained and certified workforce that could fill gaps in the mental health workforce (Eiken & Campbell, 2008; Salzer, 2010). Since the mid-20th century, individuals who have psychiatric diagnoses have been creating effective and cost-efficient services (Ostrow & Adams, 2012). Thank you for including training of peer professionals in your mental health initiative.

There was also a lack of representation of researchers, particularly researchers who have lived experience of using mental health services. Both the in-person event and the website – http://www.mentalhealth.gov – would benefit from participation by people who have a breadth of expertise in the evidence base for support of individuals experiencing psychiatric disabilities and extreme states of distress. Researchers with lived experience can offer both a perspective on the state of the science, and a nuanced interpretation of evidence for early intervention, treatment, community support, and recovery (see, e.g., Callard & Rose, 2012; Thornicroft & Tansella, 2005). The National Coalition for Mental Health Recovery (NCMHR)[2] would be pleased to send one of the members of its Research Committee (which includes master's and doctoral level researchers) to any future White House or other federal government events on this topic.

We are very concerned about the misinformation on the www.mentalhealth.gov website. Consider the following: "Schizophrenia is a severe, lifelong brain disorder."[3] Given that studies have shown that individuals can and do fully recover from even the most severe mental health conditions, including schizophrenia, calling these conditions "lifelong" is not only wrong but it can damage a person's sense of hope, which is an indispensable component of recovery. The statement that schizophrenia is a "brain disorder" is scientifically controversial, and both systematic reviews and meta-analyses confirm that biogenetic models often exacerbate the discrimination and stigma associated with mental health conditions instead of alleviating them (Angermeyer et al., 2011; Schomerus et al. 2012). Such statements are particularly irresponsible given your administration's goals of promoting inclusion, acceptance and community support, and challenging discrimination and stigma.

In response to the statement on the www.mentalhealth.gov site that "[n]o one is sure what causes schizophrenia," we refer you to the World Health Organization's (WHO, 2011) statement about the social determinants of health: ". . . the conditions in which people are born, grow, live, work and age, including the health system." WHO recognizes that these social determinants are shaped by opportunities and resources at the global, national and local levels, which are influenced by policy. These social determinants can increase health disparities and play a role in childhood and adult development, contributing to the incidence of mental health problems. In addition, studies have shown that trauma plays a key role in the development of mental health conditions. According to SAMHSA's National Center for Trauma-Informed Care (SAMSHA NCTIC, n.d.), "Although exact prevalence estimates vary, there is a consensus in the field that most consumers of mental health services are trauma survivors and that their trauma experiences help shape their responses to outreach and services."

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[2] http://www.ncmhr.org
[3] http://www.mentalhealth.gov/what-to-look-for/psychotic-disorders/schizophrenia/index.html

While it is important to continue to investigate the associations among mental health problems and factors that influence development, prevention, and access to care, please note that a decades-long WHO study found that individuals diagnosed with schizophrenia often do better in countries in the developing world – such as India, Nigeria and Colombia – than they do in such Western nations as Denmark, England and the United States (Hopper & Wanderling, 2000; Mason et al, 1996). According to an analysis of results, "Patients in developing countries experienced significantly longer periods of unimpaired functioning in the community, although only 16% of them were on continuous antipsychotic medication (compared with 61% in the developed countries). . . . The sobering experience of high rates of chronic disability and dependency associated with schizophrenia in high-income countries, despite access to costly biomedical treatment, suggests that something essential to recovery is missing in the social fabric" (Jablensky & Sartorius, 2008).

This is the time for our country to come together and repair this social fabric through support and acceptance – not alienate or erect barriers against those who are struggling. In that spirit, we strongly request that your administration actively engage our coalition in the series of dialogues unfolding over the next several months.

We believe that you and your administration are acting in good faith, and we offer these comments in the spirit of helping your administration do a better job of promoting and supporting the recovery of individuals with mental health conditions, and of combating the discrimination and prejudice associated with such conditions.

Thank you for your attention, and we look forward to a continuing dialogue with designated staff in your administration.

Sincerely,
The Board and Staff of the National Coalition for Mental Health Recovery

cc: Vice President Joseph Biden
        Secretary of Health and Human Services Kathleen Sebelius
        Secretary of Education Arne Duncan
        Substance Abuse and Mental Health Services Administration Administrator Pamela Hyde
        Center for Mental Health Services Director Paolo del Vecchio
        National Council on Disability Executive Director Rebecca Cokley
        Senator Tom Harkin
        Congressman Frank Pallone, Jr.

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