

The National Coalition of Mental Health Consumer/Survivor Organizations is united by these values:

Recovery:

We believe it is possible for everyone.

Self Determination:

We need to be in control of our own lives.

Holistic Choices:

We need meaningful choices, including a range of recovery-oriented services.

Voice:

We must be centrally involved in any dialogues and decisions affecting us.

Personhood:

We will campaign to eliminate stigma and discrimination.

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White Paper

National Recovery and Empowerment Initiative:

Active Citizens Create a Healthy Economy

January 15, 2009

Introduction: The National Coalition of Mental Health Consumer/Survivor Organizations (NCMHCSO) proposes that the federal government adopt a National Recovery and Empowerment Initiative (NREI). Only a move this comprehensive would address the multiple areas of government action necessary to create the context that persons with mental illnesses need in order to recover and to live independently in the community. The core values of the NREI would be the components of recovery agreed upon at the December 2004 consensus meeting sponsored by the Substance Abuse and Mental Health Services Administration (SAMHSA): self-determination, hope, respect, peer support, person-centered planning, empowerment, and holistic care (www.samhsa.gov/pubs/mhc/MHC_NCcrecovery.htm). The role of the federal government will be to carry out the mandate of the *Olmstead Decision*, as articulated in the report of the New Freedom Commission on Mental Health, by facilitating the transformation of the mental health system to a recovery orientation. The NREI would ensure the meaningful involvement of consumers and families in training, education, service delivery, policy, planning, evaluation, rights protection, and research at all organizational levels. (Many of these policies can be carried out at the state and county levels also.)

Overall Goal for NREI: To empower every individual to develop and recover a full life as an active citizen in his or her community

Policy 1. Public Education on wellness, resiliency, and recovery to enable all citizens to be active participants in

their communities and reach their full potential.

In order to shift the mental health system and society from an illness-based, narrowly focused approach to a holistic approach that fosters wellness and recovery, there needs to be widespread peer- and family-led public education, training and retraining the workforce.

Policy 2. Fund a network of state, regional and national consumer-run technical assistance (TA) centers and advocacy groups.

In order to ensure that mental health consumers and their families are meaningfully engaged in the transformation of the mental health system, SAMHSA will fund statewide, regional and national technical assistance/advocacy organizations.

Policy 3: Develop alternatives to hospitalization and institutionalization.

In order to reduce the costs, trauma, recidivism, and adoption of institutional roles produced by hospitalization, the National Coalition recommends community-based crisis alternatives with strong peer involvement, which would include crisis support planning, peer-run crisis centers, respite centers, in-home supports, crisis teams, warmlines, the employment of peer advocates in emergency rooms, and root-cause analysis of crises.

Policy 4: Coordination of agencies involved with recovery from mental health issues

In order to carry out the goals of the NREI, a new agency, the Mental Health Recovery and Wellness Administration, will be created. The duties of this agency will include re-evaluating the Medicaid and Medicare billing parameters for distributing money to peer-run centers. Specifically, the agency will look at how peer-run structured, scheduled activities that promote socialization, mutual encouragement, development of natural supports, and a sense of belonging and community can be included in the billable activities. This agency should provide a way for states to make suggestions as to how this can be accomplished and to identify barriers in the billing system. The new agency will also coordinate and evaluate the degree to which the funding through the Rehabilitation Services Administration, the National Institute of Mental Health, the Substance Abuse and Mental Health Services Administration, the Centers for Medicare & Medicaid Services and the Department of Housing and Urban Development promote recovery and wellness.

Policy 5: Medicaid reforms to assist in transformation to a recovery-oriented system

Medicaid and Medicare funding will be transformed from a narrow medical, institutional basis to a recovery and wellness orientation by reimbursing community-based, self-directed, peer-delivered, holistic care. A *Recovery Waiver* (in accordance with the Deficit Reduction Act) would be developed through collaboration between the consumer and family advisory board, rehabilitation experts, and Centers for Medicare & Medicaid

Services (CMS) staff. This waiver would be the primary tool by which Medicaid funding would be directed towards recovery-oriented services. The waiver would stipulate that if a state could demonstrate that it had instituted a full array of recovery and rehabilitation services, and could demonstrate that all of the mental health Medicaid expenditures are under a publicly regulated managed care contract, it could waive the IMD (Institutions for Mental Diseases: any facility with more than 16 beds in which more than 50 percent of the residents are psychiatric patients) exclusion.

Policy 5a. Personal self-determination accounts

To increase consumer control and consumer choice, persons with psychiatric disabilities should have a self-determination account, broker, and life plan by which they could budget and pay for a variety of community services that they can choose

Policy 5b: Person-driven recovery and resilience planning

Whereas traditional mental health care has consisted of professionally driven treatment planning without significant consumer or family involvement, person-centered recovery planning is a process by which the consumer's and their family's hopes and goals determine their recovery plan, with the professionals collaborating as facilitators.

Policy 5c. Medicaid reimbursement of rehabilitation services

The state Medicaid authorities narrowly interpret CMS's term "medical necessity" to mean only medically directed services, disallowing many rehabilitative services. To remedy this misinterpretation, it is proposed that CMS issue interpretive guidelines to the states that allow them to broaden the definition of medical necessity to include rehabilitative necessity and community integration, and, in so doing, fund a wider array of recovery services.

Policy 5d: Peer support reimbursement by Medicaid

Peer workers (known as Peer Support workers or Peer Specialists) have been shown to be effective in providing recovery-based services to people with psychiatric disabilities. To ensure that peer support values are always maintained in this work, training and supervision should be developed and implemented by people with lived experience of psychiatric disability.

Policy 5e: Medicaid Reimbursement of Consumer-Directed Personal Care Assistants (PCAs) in Mental Health

Though most states' Medicaid authorities will not pay for personal care assistants for people with psychiatric disabilities, the federal Medicaid guidelines authorize this service. CMS could inform the field of this by disseminating interpretive guidelines to that effect.

Policy 6: Protection of the Rights of People with Psychiatric Disabilities

We propose that people with psychiatric disabilities be treated as all other individuals, with dignity and respect, and that their right to self-determination and all other rights accorded to other members of society be protected, through the expansion of the Protection and Advocacy for Individuals with Mental Illness (PAIMI) program, to 1) include peer advocates and adequate legal representation at commitment and guardianship hearings with support for independent psychiatric assessment; (2) ensure an integrated community system, with independent living and employment and consumer-directed services; (3) close institutions and end restraint and seclusion; (4) transform the response to people in crisis as outlined in Policy 3; and (5) curtail the practice of sending children out of state for "services."

Policy 7: Safe, affordable, accessible, permanent housing, including supported housing such as the Housing First program, is needed so that individuals with mental illnesses are not warehoused in institutions, including jails and nursing homes.

The federal government as well as state governments need to make more units of affordable housing available, either through building new units or through an expansion of the Section 8 and other housing subsidy programs, and also ensure adequate funding of consumer-run housing.

Policy 8: Ensure that persons with psychiatric disabilities have an opportunity to work under the new economic stimulus package.

The stimulus package might include some specific language that the money cannot be spent without due regard to the anti-discrimination sections of the Americans with Disabilities Act, or a specialized program funded to ensure that people with mental illnesses get some of these jobs, or a mandate for one of the federal offices (such as the Department of Labor's Office of Disability Programs) to periodically monitor the role of people with disabilities as the stimulus package dollars are spent.