13 February 2006 - Testimony of Lisa Mojer-Torres for
JoinTogether's National Blueprint for States Policy Panel

I am a person in recovery; I represent others in recovery who have negotiated a diversity of paths, including medication assisted recovery. I also represent consumers of substance use illness treatment services. Many people do not understand that substance use illness is a brain disease. It is not a personality disorder, although there are often related behavioral components, and a dual diagnosis of substance use illness with a mental health disorder is not uncommon. Substance use illness is a medical disease in its own right. The medical aspects of substance use illness do not diminish responsibility for one's actions while in the throws of active addiction. However, as a chronic medical disease there are serious implications for treatment and recovery, and in a state system they are as follows:

I. Separate, Medical Model System for Substance Use Illness

The most significant implication for the individual states' efforts to prevent, treat and support recovery from the disease of substance addition is that such efforts need to occur in the context of a medical model, and not in a social services model or combination with mental health disorders under the rubric of "behavioral health." Substance use illness should be approached by the states in the identical manner other chronic diseases are approached, ie., diabetes, etc., with medical (addiction trained) physicians making initial diagnosis and treatment recommendations, etc. Although I don't pretend to have the requisite expertise to make specific systemic recommendations, I know that the current acute-care orientation is illogical, inefficient and not embraced by consumers. I also know that whatever system emerges, substance use illness warrants independence from mental health.

I recently completed service as a member of the Institute of Medicine Study Committee on "Improving the Quality of Health Care for Mental Health and Substance Use Conditions." After my pleas for separate studies (substance use illness and mental health) were rejected, the major thrust of my remaining efforts involved advocating for the unique value and particular distinctions of substance illness issues from those of mental health. Rather than discussing the issues from the perspective of what is best for consumers of substance use illness, most of my efforts were spent arguing as to why a particular issue had a different meaning for consumers of substance use illness treatment than it did for consumers of mental health services. It was a waste of resources to combine these two very different universes.

My work on the patient-centered care chapter on the issue of "coercion" provides a most compelling. In the context of mental health care, coercion typically involves restraint; is directly related to the risk of dangerousness; and the issue of concern for consumers/patients involves public exaggerations of actual threat of harm and the need to minimize, if not eliminate restraints. For substance use illness, coercion exists on a continuum; is more commonly accepted as a real factor in motivating consumers/patients to enter treatment and the major issue of concern is the quality of treatment services

received rather than how or why treatment was sought. (Research demonstrates that it is the quality of treatment services received and not the particular motivation that impacts ones ultimate success.) So, the issue of coercion would be considered a priority for the mental health advocates, while it is the quality of services received that are crucial for success in treating substance illness…

II. Treatment and Recovery Services for Substance Use Illness Should be Consumer-directed and Recovery-oriented.

The IoM's 2001 report, *Crossing the Quality Chasm: A New Health System for the 21st Century* establishes a new framework for achieving substantial improvements in health care. The framework identifies six aims of high quality health care. The third aim is that health care should be "patient-centered" which is defined as being, "respectful of and responsive to the individual patient preferences, needs, and values." And among the ten rules to guide health care re-design are that customization is based on patient needs and values and the patient is the source of control. The trend in health care of inclusion and involvement of patients/consumers at each stage of care is growing and it should not exclude substance use illness. State systems of care should be designed to meet the most common types of patient/consumer needs, but have the capability to respond individually to patient choices and preferences. Patients should be given the necessary information and the opportunity to exercise the degree of control they choose over health care decisions that affect them. The state health care system should be able to accommodate differences in patient preferences and encourage shared decision-making.

State systems of care should encourage consumers or patients of substance use illness treatment services to become involved, engaged and invested in treatment. In order to implement meaningful participation of consumer/patients in treatment and recovery decisions, states will need to facilitate informed decision-making by aggressive education initiatives. Patients and consumers should be involved in the planning, design and administration of such initiatives. And to assure outcomes are influenced by meaningful patient/consumer participation, all relevant facts, including an appreciation of both risks and options must be presented. Finally, accurate consumer satisfaction must be measured and subject to research.

Recovery –oriented care derives from the fact that substance use illness is a chronic disease for which there is no known "cure" and therefore the cessation of active substance use is but a single factor or stage of recovery. Quality of life issues are what matter most to consumers/patients/people in recovery, their families and supporters. In order to accommodate patient/consumer preferences and maintain a recovery-oriented focus, recovery support services should be encouraged and financed by the state.

III. Consumer Integration at All Levels of State Systems Planning, Administration, and Assessment

The saying "nothing about us without us" takes on significant meaning in the context of state design, delivery, funding and assessment of treatment and recovery support services.

If states are genuinely interested in "consumer-directed" treatment and recovery support services, patients/consumers and their family and supporters should be invited and involved in the design, administration, delivery and assessment phases of treatment and recovery services. Active recruitment of bona fide "consumers" who will exclusively representative the unique, distinct interests of consumers should involve the organized recovery community and consideration as to representatives' orientation, culture, diversity, etc. as qualification factors should be incorporated. Compensation and expense reimbursement issues unique to consumers should be integrated (i.e., child care expenses, out-of-pocket expenses should be minimized, etc.). Otherwise, the state runs the risk of restricting participation (and input) to those who are either independently wealthy; who have a vested interest in the issues at stake; or are otherwise employed within the field.

IV. State-Sanctioned Discrimination Laws, Policies and Practices

State-sanctioned laws, policies and practices that discriminate against people with former active substance use illness and compromise their ability to achieve sustained recovery should be identified and stopped. States should survey and analyze existing laws, policies and practices for their impact on the lives of people with former substance use illnesses. State offices charged with enforcing the laws against discrimination should be provided with a comprehensive orientation to the reality of stigma and discrimination against people in recovery from substance use illness. Federal (the Department of Justice; the Equal Employment Opportunity Commission, etc.) and local offices within the states' jurisdictions should likewise be made aware of the forms and extent of discriminatory actions impacting employment, housing, education and other social institutions. The state's judicial system should be investigated (especially drug, housing and family courts (and judges), licensing boards and other state offices to determine whether there are any discriminatory patterns or practices. State personnel, including judges should be educated as to the facts about the disease of substance use illness, efficacy and safety of the various treatment and recovery support options. Much study has been conducted on the issue of discrimination against people with substance use illness (ie., Recommendations from a National Policy Panel on "Ending Discrimination Against People with Alcohol and Drug Problems", a 2002 of JoinTogether). States should take advantage of prior work in this area and avoid duplication of efforts; the recommendations should also be integrated into states' approaches.

The criminalization of addiction perpetuates stigma, creating and reinforcing significant barriers to recovery. Those people in recovery from substance use illness who were incarcerated should not be doubly penalized upon re-entry to society. Policies that interfere with the ability to obtain employment, return to school, resume a parenting role or to fully exercise their rights as citizens of the state should be identified, examined and changed. Sentences should be fair and proportionate to those of other criminal offenses. People in recovery should not be punished repeatedly for the same offense with collateral consequences, such as those related to employment. Statutes should be amended so they do not exclude applicants based solely on their status as an alcoholic or addict and individuals should not be disqualified because of a previous non-violent drug-related offense if they can demonstrate they are in recovery and no longer breaking the law.

V. Educating Public and Policymakers about Substance Use Illness, Treatment and Recovery

As mentioned above, the general public, people with substance use illnesses, their family and supporters, policymakers and the media need to be better informed about this disease. In particular, a state-sponsored initiative aimed at criminal and family court judges would have a tremendous impact upon the quality of treatment and recovery. Information about new and developing medications for treatment and recovery as well as the growing wealth of knowledge about the biological mechanisms and chemical interactions involved in the disease of substance use illness should be made readily available, perhaps through a state-sponsored internet site, etc. In order to assure integrity and give meaning to patient/consumer participation, an educational campaign should accompany the state's efforts. A comprehensive education initiative for consumers of substance use illness treatment and recovery would begin with a survey of various treatment and recovery facilities within the state. The particular approach to treatment, including underlying treatment and recovery philosophies and a description of the various components of the treatment plan, from individual and group therapy, general and mental health assessments, 12 step participation, discharge plans, etc. Research findings on safety and efficacy of the various treatment modalities should be made available. Evidenced-based practices and statistics on outcomes should be posted for each treatment modality and each particular treatment facilities and recovery support service throughout the state. The economic costs of untreated addiction and the economics of treatment and recovery should also be presented. The world wide web/internet has proven to be an invaluable tool for the dissemination of information about addiction in that it allows for the inquirer to maintain anonymity while accessing information and posting questions. For this reason, States should take advantage of this vehicle to improve communication with the public.

Representatives Patrick Kennedy (D-MA) and Jim Ramstad (R-MN) formed the Congressional Caucus on Addiction Treatment and Recovery. That Caucus evolved into a place where members of Congress and their staffs, regardless of committee assignments or party affiliations, can become educated about addiction recovery and then educate other members about critical public policy issues. State legislatures should form similar organizations.

I currently work for a state agency (New Jersey's Division on Addiction Services) and the issues I have discussed above derive in part from that experience, but also from my life's passion and my own personal path to recovery. I am representing a population that has been beaten down by stigma and discrimination; we haven't shown our faces and our voices haven't been heard. Hopefully the numbers of our faces and the strength of our voices will begin to change how we are perceived and more importantly, how we are treated so that others can find smoother paths to recovery. Please do not hesitate to contact me if I can be of further assistance to the panel regarding the issues stated herein.

Thank you.

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