The Nation's Voice on Mental Illness

STATEMENT OF LISA HALPERN
ON BEHALF OF THE NATIONAL ALLIANCE ON MENTAL ILLNESS
ON SAMHSA REAUTHORIZATION
BEFORE THE COMMITTEE ON HEALTH, EDUCATION, LABOR AND PENSIONS
UNITED STATES SENATE

MAY 8, 2007

Chairman Kennedy, Senator Enzi and members of the Committee, I am Lisa Halpern. I currently work as Program Director of the Dorchester Bay Recovery Center, run by the Vinfen Corporation in Dorchester, Massachusetts to provide peer-directed and operated services, support and education to promote recovery. I also work at NAMI's Massachusetts affiliate as Manager of *In Our Own Voice*, an outreach and support program in which consumers help educate the public on mental illness.

Mr. Chairman, my story – just like that of millions of Americans living with serious mental illness – is unique to me. But what it does share in common is an overriding theme that recovery is possible, if the right systems and supports are in place. First, a little background on my personal story:

Unlike many people living with schizophrenia, the overt onset of the disorder occurred for me when I was already in my twenties and had already completed undergraduate studies at Duke University, having graduated summa cum laude and Phi Beta Kappa, with double majors. I then received two merit-based fellowships to study at Harvard. It was there, in June 1999, that I was first diagnosed with schizophrenia and had two stays at McLean Hospital that year. This devastating thought disorder had a profound impact on my functioning and resulted in memory loss and the inability to manage even the most basic tasks such as counting change, reading and other activities of daily living.

After one year of medical leave, I was able to return to the Kennedy School of Government at Harvard. I was fortunate to receive extraordinary support from school administrators and faculty (for example, more time for examinations and class credits for summer research). With continuing support through a Kennedy Fellowship and the Paul and Daisy Soros Fellowship for New Americans, I was able to complete my graduate studies in 2001. After completing my graduate studies, I spent two years at the Office of the Commissioner of Mental Health in Massachusetts.

In 2003, I joined a newly created assertive community treatment program in Cambridge run by Westbridge Community Services and worked as the program's first peer counselor. At Westbridge, I got my first experience supervising and working with other peer specialists, participating in a Wellness Recovery Action Plan (WRAP), offering staff

training on mental illness, and providing family and participant outreach, education and therapy for people with severe and persistent mental illness and substance abuse disorders. In 2003, I also became active in NAMI's Massachusetts affiliate as a speaker, coordinator and trainer for NAMI's *In Our Own Voice*, a recovery-based consumer speaking program.

Mr. Chairman, at the outset I would like to express NAMI's strong support for S 558, the mental illness insurance parity legislation reported by the Committee back in February. NAMI strongly supports this important measure to require employers and health plans to cover treatment for mental illness on the same terms and conditions as all other health conditions. This legislation has been stalled in the Congress for too many years. NAMI applauds your efforts to move this bill forward early in the 110th Congress. We look forward to working with you to move it to the full Senate as soon as possible.

Reauthorization of SAMHSA

Before sharing with the Committee NAMI's recommendations on legislation reauthorizing SAMHSA, I would like to echo the sentiments of the President's New Freedom Initiative Mental Health Commission report in noting that our nation's public mental health system remains a "system in shambles."

In March 2006, NAMI released a comprehensive report on the performance of states in meeting the needs of adults with serious mental illness. Our report "Grading the States" is the first comprehensive survey and grading of state adult public mental healthcare systems conducted in more than 15 years. Public systems serve people with serious mental illnesses who have the lowest incomes.

NAMI's report makes clear that nationally, the system is in trouble: the report gives the nation a grade of D for its system of care for people with serious mental illness. The report also documents that too many state systems are failing -- only 5 states received a B (Connecticut, Maine, Ohio, South Carolina, and Wisconsin), 17 states received Cs, 19 states got Ds, and 8 got Fs (Iowa, Idaho, Illinois, Kansas, Kentucky, Montana, North Dakota, and South Dakota).

Each state grade is based in part on a "take-home test," in which survey questions were submitted to state mental health agencies. All but two states responded. Colorado and New York declined. They have been graded "U" for "Unresponsive." Based on the surveys and publicly available information, states were scored on 39 criteria. Consumer and family advocates also provided information through interviews that contributed to state narratives.

The report also included a "Consumer and Family Test Drive," a unique, innovative measurement. NAMI had consumers and family members navigate the Web sites and telephone systems of the state mental health agency in each state and rate their accessibility according to how easily one could obtain basic information. The report contains a narrative for each state that also includes a list of specific "Innovations" and "Urgent Needs" to help advocates and policymakers further define agendas for action. An

overall list of innovations provides an opportunity for states to learn from one another. As the grade distribution in the report demonstrates, our nation still has a long way to go to achieve a "New Freedom" for people living with serious mental illness - a freedom based on recovery and dignity. NAMI is planning a follow-up report in 2008 and we hope to see long overdue improvements in the results.

As this Committee moves forward on SAMHSA reauthorization legislation, NAMI would urge you and your colleagues to keep these goals of recovery and independence foremost in mind. Along those lines, NAMI would make the following recommendations:

Establishment of State Outcome Measures and Accountability:

SAMHSA should be required to establish outcome measures for states, building on previous initiatives such as the National Outcomes Measures initiative (NOMS), the State Pilot indicator Grant Project, and other related initiatives. In consultation with providers, consumer and family organizations, and state mental health agencies, SAMHSA should be directed to develop measures that will provide consistent reliable information on state systems and services.

Obviously, state and local public mental health systems will need some time to adopt and implement such measures. However, as a nation we need to set ourselves toward reaching a goal for meaningful outcome measures that allow us to assess the performance of state mental health agencies and local public sector programs. In NAMI's view, the most effective means of achieving this is to have SAMHSA require every state, as a condition of receipt of funding for services and supports from the mental health block grant, Transformation State Incentive grants, and child mental health systems of care grants, to report on all outcome measures developed by SAMHSA.

It is also worth noting that while some reporting on the types of services provided is required under current law, these reporting requirements are not generally linked in any way to evidence-based practices that are designed to deliver measurable outcomes in terms of recovery such as integrated treatment for individuals with co-occurring mental illness and substance abuse, assertive community treatment (ACT), peer counseling and supports, multi-systemic therapy for children and adolescents, and family psycho-education, to name just a few.

Despite years of discussion in the mental health field about evidence-based practice, we are still falling short on uniform data on the availability of these services across states or regions or the degree to which programs that provide these services achieve fidelity to standards developed by SAMHSA itself. SAMHSA authorization provides us with an important opportunity to make progress toward this objective.

Establishment of Federal Interdepartmental Task Force on Mental Health.

NAMI supports the creation of a Federal Interdepartmental Task Force on Mental Health that should include involvement from the vast array of federal agencies that administer programs that touch the lives of children and adults living with mental illness and substance abuse disorders. This should include the Secretaries of Housing and Urban Development, Labor, Education, Veterans Affairs, Health and Human Services (including CMS, SAMHSA, CDC, NIH and HRSA), the Social Security Administration) and the Attorney General. The goals of this Task Force should include:

1. improved coordination of mental health policy in the operation of pertinent federal programs;
2. identification of policies and practices that contribute to fragmentation in care-delivery and barriers to care-integration;
3. development and implementation of interagency demonstration programs to foster mental health promotion, early intervention, and recovery-focused services; and
4. an annual report to Congress from the respective Secretaries which shall include recommendations for fostering improved collaboration and coordination of mental health policy, financing and management of recovery-focused service-delivery.

Program Sustainability through Consumer and Family Engagement

SAMHSA has made enormous progress in recent years integrating the views of consumers and families into every major activity at the agency. This is a tremendous step forward. Unfortunately, this progress is not always mirrored at the state and local level. In order to jump start this process at the state and local level, SAMHSA and CMHS should be granted the authority to require state and local government recipients of SAMHSA funding above a specific threshold to allocate at least 5% of such funds to one or more not-for-profit organizations that represent consumers and families, to ensure that such organizations are able to participate in all aspects of planning and implementation of the SAMHSA grant or program.

Reducing the Use of Seclusion and Restraint

When SAMHSA was last reauthorized by Congress in 2000, this Committee included a new Part H that contained requirements pertaining to the rights of residents of hospitals (private and public), nursing facilities, intermediate care facilities, or other health care facilities that receive federal funds, including restrictions on the use of restraints and seclusion. NAMI supports expansion of these requirements through establishment of a new training and technical assistance center to focus on the prevention of seclusion and restraint in public and private facilities that provide mental health services to adults and children. Such training and technical assistance should include assisting states in facilitating the use of psychiatric advance directives for consumers in the community and the implementation of PADs by facilities.

It must also be pointed out that although the Children's Health Act of 2000 required that regulations be promulgated to give effect to Part H within one year of enactment, these

regulations have never been issued by SAMHSA. Although some progress has been made in reducing the inappropriate use of restraints and seclusion, far too many children and adolescents continue to die or suffer serious injuries resulting from the inappropriate use of these aversive measures. Thus, we urge the Committee to include in statute specific standards pertaining to restraints and seclusion in facilities and programs covered under Part H. At a minimum, these should include:

- Requiring that thorough and comprehensive face to face evaluations of all individuals placed in restraints or seclusion be conducted by a physician or licensed independent practitioner within one hour of the time that these measures are instituted.
- Continuous monitoring of individuals in restraints or seclusion, either face to face, or using video and audio equipment.
- Debriefing of staff involved in the use of restraints or seclusion after each incident, preferably involving the individual subjected to these measures as part of the debriefing process. Debriefing has been shown to be very effective in sensitizing staff to alternative, less draconian measures for deescalating crises.
- Limits on the length of orders authorizing the use of restraints and seclusion to one hour for individuals under 18 and two hours for adults.
- Requirements that all deaths and serious injuries that occur within one week of the time restraints or seclusion are used must be reported by the facility in which these measures were instituted to the designated Protection and Advocacy agency located in the state in which these deaths or serious injuries occur. Additionally, all deaths and serious injuries that occur beyond one week of the time restraints or seclusion that can reasonably be assumed to be related to the use of these measures should be reported as well.

Separate Legislative Proposals for SAMHSA Reauthorization

NAMI recommends that this Committee consider amending any SAMHSA reauthorization bill to add separate legislation that would improve the performance of our nation's mental health system and benefit the most vulnerable children and adults living with mental illness

Reauthorization of the Garrett Lee Smith Memorial Act -- Suicide remains the third leading cause of death for those between the ages of 10 and 24 and the second leading cause of death for American college students. Programs under the Garrett Lee Smith Act (first authorized by Congress in 2004) have been highly successful helping states and localities, as well as colleges and universities address this epidemic. This Committee should reauthorize and expand this highly successful program.

Keeping Families Together Act (S 382) – Every year, thousands of families across the country are forced to give up custody of their children to the child welfare and juvenile justice systems to secure mental health services. The Keeping Families Together Act – introduced by your colleague Senator Susan Collins – is an important effort to keep children with mental illnesses who are in need of services at home and in their

communities and most importantly, with their families. It encourages states to build effective systems of care for children with mental illnesses and their families and move away from costly residential and institutional services that too often require families to transfer custody of their children to the state to access these costly services.

Services for Ending Long-Term Homelessness Act (S 593) – In order to make continued progress toward the national goal of ending chronic homelessness by 2012, it is critical for HHS and SAMHSA to step up and increase investment in services in permanent supportive housing that are needed to help people with mental illness and co-occurring substance abuse disorders from falling back into chronic homelessness. SELHA – introduced by Senators Richard Burr and Jack Reed – achieves this critical goal and should be a part of SAMHSA reauthorization legislation.

Thank you for giving me this opportunity to provide input to the Committee.