Walker Testimony
Sub-Committee on Substance Abuse and Mental Health Services - SAMSHA Reauthorization
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Testimony:
Chairman DeWine, Senator Kennedy and members of the Subcommittee, I am Gloria Walker of Cincinnati, Ohio. Since 2000, I have served on the Board of Directors of the National Alliance for the Mentally Ill (NAMI). I am also a Past President of NAMI Ohio, having served in that capacity from 1998 until 2000. I am also the mother of a son who has struggled with mental illness for nearly 20 years. It is from these perspectives – a leader in the NAMI movement and as a family member – that I offer the following views on the future of SAMHSA and the need to improve the federal government's response to the growing crisis in our public mental health system.
Who is NAMI?
NAMI is a nonprofit, grassroots, self-help, support and advocacy organization of consumers, families, and friends of people with severe mental illnesses, such as schizophrenia, schizoaffective disorder, bipolar disorder, major depressive disorder, obsessive-compulsive disorder, panic and other severe anxiety disorders, autism and pervasive developmental disorders, attention deficit/hyperactivity disorder, and other severe and persistent mental illnesses that affect the brain.
Founded in 1979, NAMI today works to achieve equitable services and treatment for more than 15 million Americans living with severe mental illnesses and their families. Hundreds of thousands of volunteers participate in more than one thousand local affiliates and fifty state organizations to provide education and support, combat stigma, support increased funding for research, and advocate for adequate health insurance, housing, rehabilitation, and jobs for people with mental illnesses and their families. Local affiliates and state organizations identify and work on issues most important to their community and state. Individual membership and the extraordinary work of hundreds of thousands of volunteer leaders is the lifeblood of NAMI's local affiliates and state organizations.
I am pleased today to submit the following testimony on behalf of the National Alliance for the Mentally Ill (NAMI) on legislation to reauthorize the Substance Abuse and Mental Health Services Administration (SAMHSA).
Public Mental Health System In Crisis
Mr. Chairman, as you know in a matter of days President Bush's Commission on Mental Health (chaired by our own Mike Hogan of Ohio) will be releasing its final report. We expect this report will document what too many NAMI members know from personal experience – that the public mental health treatment and support system in most states is in serious disrepair. In fact, as the Commission noted in its Interim Report last fall, this "system" is in fact not a coherent system, but rather a fragmented and underfunded series of programs crossing multiple layers of government with little accountability and coordination. I can tell you from personal experience that this confusing system

overwhelms consumers and families with conflicting eligibility rules and reliance on service models that are inconsistent with the enormous scientific advances that have been made in recent years with respect to recovery-oriented interventions for severe mental illness.

The result of this system in collapse is that children and adults living with severe mental illness are increasingly over-represented in the chronic homeless population and in local jails and prisons. The failure of this system is also reflected in our nation's alarmingly high suicide rate. This year NAMI completed its most comprehensive survey of our consumer and family membership – 3,400 respondents. The findings are alarming. Nearly half of the consumer respondents reflected in the survey had been hospitalized within the past 12 months and 40 percent needed emergency services. Fewer than one-third received evidence-based, recovery-oriented services such as assertive community treatment programs, supported employment services, and substance abuse treatment. More troubling is that the lack of appropriate treatment translated into extensive involvement with the criminal justice system—43% of the consumers in the NAMI survey have been arrested or detained by police.

SAMHSA's Response to the Growing Crisis in the Public Mental Health System

Given SAMHSA's limited resources ($3.2 billion in a system estimated to consume more than $44 billion), it is unrealistic (and probably unwise) to expect the agency to assume responsibility for complete reform of the complicated and fragmented system that consumers and families must navigate. At the same time, SAMHSA can (and should) play a leadership role in assisting states and localities in modernizing and reforming the way mental illness treatment and supports are delivered. Reauthorization legislation therefore affords an important opportunity for Congress to sharpen the agency's mission to assist state and local mental health authorities in this effort.

NAMI is pleased that the Bush Administration has appointed three leaders with experience in running state mental health authorities to manage SAMHSA and the Center for Mental Health Services (CMHS): Administrator Charles Curie of Pennsylvania, Deputy Administrator James Stone of New York and CMHS Director Kathryn Power of Rhode Island. Each brings vast experience in managing and reforming services and working with NAMI organizations at the state and local level.

NAMI Recommendations for SAMHSA Reauthorization

SAMHSA needs to provide stronger leadership in bridging the divide between science and practice to ensure wider replication of evidence-based practice

Over the past five years, SAMHSA has made enormous progress in transforming its programs to create a stronger grounding in science and enhanced emphasis on replication of evidence-based practice. NAMI supports this effort to refine and sharpen SAMHSA's mission to ensure that it is firmly grounded in furthering investment in clinical treatment and that service models are informed by research and recovery-oriented outcomes. This shift is beginning to take place as part of SAMHSA's Programs of Regional and National Significance (PRNS) which funds community action grants and targeted capacity expansion in priority areas such as assertive community treatment, jail diversion, suicide prevention and treatment for co-occurring disorders.

NAMI is also supportive of efforts by SAMHSA to develop a new level of cooperation with colleague agencies at the National Institutes of Health (NIH). It is critically important for SAMHSA and NIH to develop a more workable partnership with respect to

services research and services demonstration studies that assess how best to deliver clinical services in real world settings. This is especially the case given the challenges particular to the real world settings in which children and adults are increasingly receiving services: homeless shelters, emergency rooms, jails, juvenile justice facilities, schools and primary care. Both agencies have strengths that need to be effectively coordinated to develop a stronger research base on service delivery and technical assistance capacity for pushing state and local authorities and front-line providers to invest in evidence-based practice.

NAMI therefore recommends that this Subcommittee redirect SAMHSA to its core mission of assisting state and local mental health agencies in bridging the gap between science and practice, with particular focus on replication of evidence-base practices grounded in recovery-oriented services for children and adults living with severe mental illnesses.

SAMHSA needs to provide stronger leadership in improving the data infrastructure capacity of the public mental health system

In 2000, Congress directed SAMHSA to convert its separate substance abuse and mental health block grant programs to "Performance Partnership Grants" (PPGs). The objective was to reform these block grant programs to promote greater emphasis on evidence that measure the performance of states in meeting specific goals, and away from expenditure reports tracking where and how funds are spent. NAMI applauded this effort as part of a larger strategy designed to push states to begin developing better data systems that actually measure progress in meeting outcomes related to treatment, recovery and provider performance.

While SAMHSA has met the goal of converting the block grants to PPGs, NAMI believes that further steps need to be taken to finally put in place effective data collection and dissemination systems. NAMI believes that such a data infrastructure should be able to measure not only performance outcomes achieved with funds allocated through SAMHSA, but all state and local resources as well, whether or not those dollars directly flow through the state mental health authority or other sources (e.g. Medicaid). As was the case with conversion to the PPG model, such data systems should be able to facilitate assessment of progress towards specific outcome measures and an unduplicated count of who is being served.

NAMI has long been frustrated with the lack of a coherent system of data collection for public mental health spending. The inability to compare and measure the performance of state public mental health systems has been a major impediment to progress in seeking adequate resources to fund public sector programs. After years of frustration, NAMI has acted on its own to establish TRIAD – the Treatment, Recovery, Advocacy and Information Database. This is our own effort to develop a set of measures to assess the performance of states tied to recovery for consumers and their family members. As excited as we are about the data being generated by TRIAD, we are nonetheless discouraged that the inconsistencies of data collection and dissemination systems across the states and SAMHSA still prevents meaningful comparisons across the states.

SAMHSA should be encouraged to continue its mission to make treatment for co-occurring mental illness and substance abuse disorders a priority

NAMI is especially pleased that SAMHSA Administrator Curie has placed such a high

priority on addressing the needs of the estimated 10 million Americans who have co-occurring mental illness and substance abuse disorders. SAMHSA's November 2002 report to Congress (mandated by this Committee in 2000) is an important step forward in compiling existing data on the extent of the problem and current research on effective clinical interventions. NAMI agrees that there should be "no wrong door" for entering treatment for individuals with co-occurring disorders.

NAMI also agrees that the existing research literature clearly demonstrates that neither mental illness, nor chemical dependency treatment, can be effective unless both are provided in an integrated fashion through interdisciplinary coordination. However, despite this report we are still seeing too little investment from the separate mental health and substance abuse systems in integrated mental health and substance abuse treatment. NAMI believes that accounting and regulatory burdens are still serving as a barrier to fostering development of integrated treatment by state and local agencies. NAMI would therefore urge this Subcommittee to consider statutory language to make it clear that states may utilize funds from the Mental Health and Substance Abuse PPGs to provide integrated treatment to individuals with co-occurring disorders.

SAMHSA should play a stronger role in helping to meet President Bush's goal of ending chronic homelessness over the next decade

As you know, President Bush (through the leadership of the White House Interagency Council on the Homeless) has put forward his "Samaritan Initiative" to end chronic homelessness over the next decade. In addition, Secretary Thompson has put in place his own plan for all HHS agencies to address chronic homelessness. NAMI supports these efforts, but also believes that SAMHSA can do more to ensure that its programs more effectively address the needs of individuals with severe mental illness and co-occurring disorders experiencing chronic homelessness (i.e., staying homeless for a year or more). First, as part of the Samaritan Initiative, Congress should authorize and fund a new program to finance services in new and existing permanent supportive housing developed by HUD's McKinney-Vento Homeless Assistance Act. NAMI, along with our colleagues at the National Alliance to End Homelessness and the Corporation for Supportive Housing, have our own proposal on services in permanent supportive housing – ELHSI (Ending Long-Term Homeless Services Initiative). What is key is that existing and future permanent supportive housing have stable funding for services to ensure that individuals are able to make the transition to stable lives in the community.

Finally, NAMI would urge this Subcommittee to examine the current problems with the funding formula associated with the PATH program at CMHS (Projects for Assistance in Transition from Homelessness). This critically important program funds outreach and engagement services for homeless individuals in shelters and on the streets. Since FY 1997, Congress has nearly doubled funding for PATH, up to $50 million requested for FY 2004. Unfortunately, more than 20 rural and frontier states have seen their allocation of PATH funds frozen as a result of artificially low minimum state allocation. Likewise, the current formula resulted in four states (Alabama, Missouri, New York and Ohio) actually losing funds in FY 2003 despite a $3 million increase provided by Congress.

SAMHSA should expand its efforts to address the growing and disturbing trend of "criminalization" of mental illness experienced by adults in jails and prisons and adolescents in juvenile justice programs

Chairman DeWine, NAMI is extremely grateful for the leadership that you have provided

in Congress in bringing attention to this enormous and growing problem. NAMI strongly supported your efforts in passing legislation authorizing the Mental Health Courts program at the Justice Department (P.L. 106-515). NAMI is proud to support your legislation (S 1194) to expand the ability of state and local law enforcement and corrections systems to cope with their growing burden of responding to offenders with a history of untreated severe mental illness – most of them low-level non-violent offenses. As you know, effective jail diversion programs, Mental Health Courts, and programs to help adult and juvenile offenders with mental illnesses transition back into the community require close collaboration and cooperation between corrections, courts and mental health systems. Too often, mental health systems have been reluctant to do their part to help these individuals, many of whom would not have ended up in correctional systems had they received timely and appropriate mental health services and supports. At the Federal level, SAMHSA has worked collaboratively with the Department of Justice to provide technical assistance and support for jail diversion and community reentry programs for offenders with mental illnesses.

NAMI strongly urges that the SAMHSA reauthorization legislation be utilized as an opportunity to expand the agency's current jail diversion program and to expand the jurisdiction of this program to include community reentry and transition for juveniles and adults with mental illnesses exiting criminal justice systems. We also urge that SAMHSA be encouraged to work even more closely with the Department of Justice and other relevant Federal Agencies (e.g. the Social Security Administration, the Center for Medicaid and Medicare Services, and the Department of Housing and Urban Development) in carrying out these important activities.

SAMHSA should continue its efforts to address the absence of a coherent service system for children and adolescents with serious mental illness

The impending release of President Bush's New Freedom Commission report on Mental Health will emphasize the wholesale fragmentation and lack of coordination between various systems responsible for providing treatment and services to individuals with mental illnesses across the country. These problems are particularly profound for children and adolescents who suffer from mental illnesses. It is well documented that families of children with mental illnesses frequently have no place to turn to access the services that their children need. As a consequence, children with mental illnesses are even more disproportionately represented in juvenile justice systems than adults with mental illnesses are in adult correctional systems. Moreover, many families are literally forced to give up custody of their children to access care for their loved ones. This is a national tragedy.

As a first step, NAMI recommends that Congress establish, through legislation, an interagency body on children's mental health to improve collaboration, systems coordination, and blended funding of services for children with mental illnesses across all relevant federal programs. SAMHSA, as the nation's lead agency for mental health services, should be vested with lead responsibility for this important function.

Additionally, CMHS – through the Children's Mental Health Services Program also funds the Comprehensive Community Mental Health Services for Children and Their Families Program – provides grants to public entities providing comprehensive community-based mental health services for children and adolescents with mental illnesses. NAMI strongly supports the federal investment in creating home and

community based services for children with mental illnesses and their families. We look forward to working with the Subcommittee to ensure that the program is further improved so that children and adolescents with serious mental illnesses receive services that are evidence-based, effective and associated with that outcomes that are tracked to ensure accountability.

Conclusion

NAMI is deeply grateful for the opportunity to offer our views on SAMHSA reauthorization legislation. We look forward to working with you and your colleagues on this legislation and other matters that will come before this Subcommittee.