



**STATEMENT OF MARY GILIBERTI
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TO THE LABOR-HHS-EDUCATION SUBCOMMITTEE
COMMITTEE ON APPROPRIATIONS
UNITED STATES SENATE
REGARDING FY 2015 FUNDING FOR THE NATIONAL INSTITUTE OF MENTAL
HEALTH (NIMH) AND THE SUBSTANCE ABUSE AND MENTAL HEALTH
SERVICES ADMINISTRATION (SAMHSA)**

MAY 23, 2014

Chairman Harkin and members of the Subcommittee, I am Mary Giliberti, Executive Director of NAMI (the National Alliance on Mental Illness). I am pleased today to offer NAMI's views on the Subcommittee's upcoming FY 2015 bill. NAMI is the nation's largest grassroots advocacy organization representing persons living with serious mental illness and their families. Through our 1,100 affiliates in all 50 states, we support education, outreach, advocacy and research on behalf of persons with serious mental illness such as schizophrenia, manic depressive illness, major depression, severe anxiety disorders and mental health conditions affecting children.

An estimated 11.5 million American adults live with a mental illness, such as schizophrenia, bipolar disorder, and major depression. Based on estimates for 2010, mental disorders accounted for 21.3 percent of all years lived with disability in the United States. Among the top 20 causes of years lived with disability, five were mental disorders: major depressive disorder (8.3 percent of the total), anxiety disorders (5.1 percent), schizophrenia (2.2 percent), bipolar disorder (1.6 percent) and dysthymia (1.5 percent). Suicide is the 10th leading cause of death in the US, accounting for the loss of more than 38,000 American lives each year, more than double the number of lives lost to homicide. The social and economic costs associated with these disorders are tremendous. A cautious estimate places the direct and indirect financial costs associated with mental illness in the U.S. at well over \$300 billion annually, and it ranks as the third most costly medical condition in terms of overall health care expenditure, behind only heart conditions and traumatic injury.

These costs are not only financial, but also human in terms of lost productivity, broken families and lives lost to suicide. Investment in mental illness research and services are – in NAMI's view – the highest priority for our nation and this Subcommittee.

National Institute of Mental Health (NIMH) Research Funding

As a member of the Ad Hoc Group for Medical Research Funding, NAMI supports a \$32 billion overall allocation for the National Institutes of Health (NIH). This increase is needed to avoid having our country continue to fall behind China, India and other emerging nations in terms of our public investment in scientific research. As you know, the President is requesting a \$23 million increase for the NIMH for FY 2015, boosting funding for the agency to \$1.44 billion. NAMI would urge the Subcommittee to fund investments beyond this amount with an overall higher allocation for the entire NIH.

NAMI also supports the President's BRAIN Initiative (Brain Research through Advancing Innovative Neurotechnologies) and the request for a \$40 million boost, up to \$100 million. The BRAIN Initiative is multi-agency collaborative with a number of foundations designed to unleash new technologies and undertake basic mapping of circuits and neurons in the most complex organ in the human body.

Accelerating the Pace of Psychiatric Drug Discovery

In NAMI's view, there is an urgent need for new medications to treat serious mental illness. Existing medications can be helpful, but they often have significant limitations; in some cases requiring weeks to take effect; failing to relieve symptoms in a significant proportion of patients; or, resulting in debilitating side effects. However, developing new medications is a lengthy and expensive process. Many promising compounds fail to prove effective in clinical testing after years of preliminary research. To address this urgent issue, NAMI is encouraging NIMH to accelerate the pace of drug discovery through an 'experimental medicine' approach to evaluate novel interventions for mental illnesses. This "fast-fail" strategy is designed not only to quickly identify candidates that merit more extensive testing, but also to identify targets in the brain for the development of additional candidate compounds. Through small trials focused on proof-of-concept experimental medicine paradigms, we can make progress to demonstrate target engagement, safety, and early signs of efficacy.

Advancing Services and Intervention Research

NAMI enthusiastically supports the NIMH Recovery After an Initial Schizophrenia Episode (RAISE) Project, aimed at preventing the long-term disability associated with schizophrenia by intervening at the earliest stages of illness. The RAISE Early Treatment Program (RAISE ETP) will conclude this year. The RAISE Connection Program has successfully integrated a comprehensive early intervention program for schizophrenia and related disorders into an existing medical care system. This implementation study is now evaluating strategies for reducing duration of untreated psychosis among persons with early-stage psychotic illness. When individuals with schizophrenia and bipolar disorder progress to later stages of their illness, they become more likely to develop—and die prematurely—from medical problems such as heart disease, diabetes, cancer, stroke, and pulmonary disease than members of the general population. NIMH funded research is demonstrating progress advancing the health of people with serious mental illness. NIMH needs to advance this research to large-scale clinical trials aimed at reducing premature mortality for people living with serious mental illness.

Investing in Early Psychosis Prediction and Prevention (EP3)

As many as 100,000 young Americans experience a first episode of psychosis (FEP) each year. The early phase of psychotic illness is a critical opportunity to alter the downward trajectory and social, academic, and vocational challenges associated with serious mental illness such as schizophrenia. The timing of treatment is critical; short- and long-term outcomes are better when individuals begin treatment close to the onset of psychosis. Unfortunately, the majority of people with mental illness experience significant delays to seeking care—up to nine years in some cases. Such delays result in periods of increased risk for poor outcomes, especially suicide.

NIMH-funded research has focused on the prodrome, the high-risk period preceding the onset of the first psychotic episode of schizophrenia. Through North American Prodrome Longitudinal Study (NAPLS) and other studies focused on early prediction and prevention of psychosis, NIMH has launched Early Psychosis Prediction and Prevention (EP3) initiative. EP3 is showing promise in detecting risk states for psychotic disorders and reducing the duration of untreated psychosis in adolescents that have experienced FEP.

Advancing Precision Medicine

NAMI supports efforts at NIMH to translate basic research findings on brain function into more person-centered and multifaceted diagnoses and treatments for mental disorders. The Research Domain Criteria

(RDoC) is showing promise toward efforts to build a classification system based more on underlying biological and basic behavioral mechanisms than on symptoms, RDoC should begin to give us the precision currently lacking with traditional diagnostic approaches to mental disorders.

Funding for Programs at SAMHSA’s Center for Mental Health Services (CMHS)

As noted above, the costs of untreated mental illness to our nation are enormous – as high as \$300 billion when taking into account lost wages and productivity and other indirect costs. These costs are compounded by the fact that across the nation states and localities devote enormous resources addressing the human and financial costs untreated mental illness through law enforcement, corrections, homeless shelters and emergency medical services. This phenomenon of “spending money in all the wrong places” is tragic given that we have a vast array of proven evidence-based interventions that we know work – assertive community treatment, supported employment, family psycho-education and supportive housing.

NAMI supports programs at the Center for Mental Health Services (CMHS) at SAMHSA that are focused on replication and expansion of these evidence-based practices that serve children and adults living with serious mental illness. The most important of these programs is the Mental Health Block Grant (MHBG). NAMI is extremely grateful for the increases in funding for the MHBG that this Subcommittee has made in recent years, boosting funding from \$420 million in FY 2010, up to its current level of \$484 million in in FY 2014. This increase has been important to helping states fills gaps in services that have occurred as states cut more than \$4 billion from state mental health budgets since the recession began in 2008.

NAMI also supports the 5 percent set aside in the in the MHBG that this Subcommittee enacted in FY 2014 for early intervention in psychosis. As noted above, the NIMH RAISE study validated the most effective approaches for providing coordinated care for adolescents experiencing FEP. Among these is Coordinated Specialty Care (CSC), a collaborative, recovery-oriented approach that emulates the assertive community treatment combining evidence-based services into an effective package. CSC emphasizes shared decision-making—which NAMI strongly supports—with the recipient of services taking an active role in determining treatment preferences and recovery goals.

In April, CMHS issued guidance to the states specifying that funding as part of the 5 percent set aside must be used for those who have developed the symptoms of early serious mental illness, not for “preventive intervention for those at high risk of serious mental illness.” NAMI supports this guidance and we recommend that the Subcommittee continue this 5 percent set aside for FEP in FY 2015 and beyond.

NAMI would also recommend the following priorities for CMHS for FY 2015:

- Continuation of the Children’s Mental Health program at \$117 million, and
- Support the President’s proposal for a \$6 million increase for suicide prevention activities at CMHS (up to \$54.2 million), including funding for the Garrett Lee Smith Memorial Act.

Addressing Early Mortality and Serious Mental Illness, Integrating Primary and Behavioral Health Care

The CMHS Primary Behavioral Health Care Integration (PBHCI) program supports community behavioral health and primary care organizations that partner to provide essential primary care services to adults with serious mental illnesses. Because of this program, more than 33,000 people with serious mental illness and substance use disorders are screened and treated at 100 grantee sites for diabetes, heart disease, and other common and deadly illnesses in an effort to stem the alarming early mortality rate from these health conditions in this population. NAMI urges the Subcommittee to fund the PBHCI for FY 2015 at \$50 million.

Addressing the Needs of Homeless Individuals Living with Serious Mental Illness

On any given night, according to 2013 data, 610,042 people are homeless, and 15 percent of these individuals are defined as long-term or chronically homeless. Years of reliable data and research demonstrate that, for single individuals with serious mental illness who live with complex needs, the most successful intervention for ending and preventing homelessness is linking housing to appropriate support services. Although there is a need for more affordable housing, funding the supportive services is even more difficult. SAMHSA homeless programs fill a gap created by a preference of HUD to fund housing rental assistance and capital needs. HHS must take responsibility to fund the critically important services that are necessary for programs to be effective.

In 2013, SAMHSA was not able to award any new community-based services grants. For the first time, eleven states (AZ, GA, HI, WA, LA, IL, NV, PA, MA, MI and CO) did receive funding to improve statewide alignment of resources but every state could use SAMHSA assistance in their efforts to end homelessness. Over the years, hundreds of government entities and local providers have been unable to move forward with important work due to inadequate funding levels. The current FY 2014 funding level of SAMHSA homeless programs is \$74 million, divided between CMHS and CSAT. NAMI supports an increase for this joint program up to \$100 million, equally divided between CMHS and CSAT.

NAMI also supports funding for the PATH program (Projects for Assistance in Transition from Homelessness) that allocates funds by formula to states to serve homeless people with serious mental illness. Eligible services include outreach, screening and diagnosis, habilitation and rehabilitation, community mental health services, substance abuse treatment, case management, residential supervision, and housing. PATH supported programs reached over 191,839 people in fiscal year 2013. Of these, 65 percent were unsheltered at the time of engagement, 42 percent were not engaged in mental illness treatment and 53 percent had co-occurring substance use disorders. NAMI recommends at least \$75 million for the PATH program for FY 2015 (the authorized amount). In FY 2014, the PATH program is funded at \$65 million.

Conclusion

Chairman Harkin, thank you for the opportunity to share NAMI's views on the Labor-HHS-Education Subcommittee's FY 2015 bill. NAMI's consumer and family membership thanks you for your leadership on these important national priorities.