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Senate Committee on Health, Education, Labor and Pensions. January 24, 2013 Hearing
<u>Assessing the State of America's Mental Health: What We Can Do Now</u>

The mental health community appreciates the attention of the Committee, and the concern for consumers, families and providers that it represents. Mental health needs are substantial, but such attention from policy-makers is rare.

What is the state of the mental health system? A decade ago, a commission appointed by President George W. Bush to review mental health care told the president that despite the efforts of many dedicated people "the Unites States mental health services delivery system is in shambles." While many of the challenges we addressed still exist, problems and solutions are clearer a decade later. I hope we can provide you with a helpful picture of them.

Much has changed, while much appears to remain the same. The Nation's mental health system had its origins in the asylums of the 19<sup>th</sup> century. While much has been said about the balance between institutional and community care, a bigger issue is that for most of our history, mental health care has been separate from health care—and also unequal. In the best recent study of mental health policy, Richard Frank and Sherry Glied assessed whether people with a mental illness were better off early in this century than 50 years earlier. They answered that question in the name of their monograph: "Better, but not well." However, the main insight from their study is that the improved well-being of people with a mental illness is not mainly due to changes within mental health care. Rather, the well-being of people with mental illness improved as they gained access to mainstream benefits like health care, disability insurance and housing. Improvements within the mental health system, like new treatments, had a smaller effect.

This trend has now accelerated. A major example is legislation known by the two outstanding Senators, a political odd couple united by concern for mental health, who sponsored it: Pete Dominici and Paul Wellstone. The 2007 passage of the Mental Health Equity and Addictions Parity Act (MHEAPA) was not about improvements within the mental health system. It was about including mental illness care in health care. It signaled that a separate and unequal mental health system was not an adequate solution.

Mental health care was also greatly enhanced by passage of the <u>Patient Protection and Affordable Care Act</u> (ACA). Building on Dominici-Wellstone, the ACA included mental health within its changes to health care. These two pieces of legislation are game changers for mental health. The inclusion of mental health will lead to profound changes that will play out over the next generation. Because health care is so complex and change is unpredictable, there will be false starts and dead ends. But any assessment of the state of America's mental health system must begin with a realization that we have begun to take big steps away from an approach that was both separate and unequal. The major challenges facing us are first whether including mental health in health care can be done sensibly, and second whether the portions of the mental health safety net that have value can be sustained. Inclusion creates big opportunities that we can seize or let slip away. In an earlier era of deinstitutionalization, we did not sustain our commitments to those most in need during change. Can we get it right this time?

Integrating mental health care into health care. A first major challenge for the next decade is to integrate basic mental health care into primary care. (Integrating primary medical care into mental health centers is also important, but not my major focus here.) We know that most Americans with mental health problems get no treatment for these problems. We also know that more people are treated by their family physician or other primary care practitioner than by mental health specialists. The problem is that we have many unmet needs while many specialty mental health programs are at capacity. The opportunity before us is that health coverage that includes mental health care will become available for many Americans. We must use this opportunity to provide integrated primary care that includes basic mental health care. There is less stigma in visits to primary care. People with a chronic illness like diabetes, cancer or hypertension who also have depression have health care costs at least 50% higher; and good basic mental health care reduces overall costs. Improving basic mental health care in primary care is a huge need and opportunity.

It will not occur automatically. Mental health care within primary care today is often inadequate. It can be done well, improving health and reducing costs, but barriers must be addressed. For example, "carved out" benefits for mental health care can usually be used only if a specialist is seen. Across primary care settings that have not upgraded to provide integrated care, less than half of the patients with a mental health problem get a mental illness diagnosis and treatment. Payments and supports for basic mental health care in primary care are often lacking, so less than 15% of the people with depression in primary care get adequate care. As a result, people with medical conditions like diabetes or high blood pressure as well as a mental health concern have bad health outcomes and higher medical costs.

We have an opportunity to address this problem because many people with these conditions will now have insurance that includes mental health care, and because practical ways to deliver basic mental health care in primary care settings are now well established. The approach, known as collaborative care, improves both health and mental health outcomes and also reduces total costs. Collaborative care is research tested and replicated in many real world clinics. The move to integrated care takes work, but its core elements are not complex: station a mental health practitioner in the practice, screen for mental health problems, measure progress, allow billing for basic mental health services like educating patients about managing their depression and ensure a psychiatrist or other specialist is available for consultation.

While collaborative care is proven, barriers to integrated care like separate benefits that are not available to primary care must be addressed. For collaborative care to work, the primary care setting must have its costs covered, including the modest additional costs of providing integrated care. There are also barriers in federal standards. Medicare still does not pay adequately for the elements of collaborative care, despite the terrible burden of depression and other mental health challenges for older Americans. National screening recommendations are also outdated. They say, in effect, "If you have plenty of resources to treat depression, you ought to screen for it." This is ridiculous. In my view, removing obstacles to primary care treatment of basic mental health problems is a core element of getting mental health parity right. It would be timely and very helpful if the Committee were to track progress toward integrated care.

Protecting the safety net. While health reform creates opportunities to improve care for many Americans, the safety net for individuals with the most serious mental illness is very stressed. This system, which evolved from state asylums and mental health centers to a diverse array of community based treatment, rehabilitation and support services, is directed and managed at the state and sometimes the county level. Its financing depends on Medicaid and state general funds. And given state budget shortfalls, resources have been cut. The National Association of State Mental Health Program Directors (NASMHPD) indicates that state mental health funding was reduced by more than \$4B between 2009 and 2012.

While these cuts have been damaging, in many states the mental health safety net is stronger than it was a quarter century ago. Dedicated providers as well as state and local officials have learned what works. For example, we understand that decent, safe and affordable housing is a foundation for recovery, and a "Housing First" approach that first finds homeless mentally ill people a place to live and then assists with health and mental health has become a usual approach. We understand that people in recovery from mental illness and addiction working as "peer specialists" play an invaluable role as staff of community agencies. Many community mental health agencies are also integrating medical services into their mental health clinics, to address the co-occurring medical problems of the people they serve. So while the mental health safety net is stretched to the limits, it is better focused and more relevant than in the past.

There are threats to the safety net as health reform proceeds. Budget cuts have taken their toll, and we hope that as states move past budgets depleted by the recession there will not be further deep cuts. But there is also a concern about the erosion of informed leadership for the safety net system. Within states, as Medicaid has become the dominant payer for mental health services, the mantle of leadership is swinging away from mental health (and addiction) agencies toward Medicaid and Health agencies. A similar trend is occurring at the level where health care is managed; there is a movement toward managed care and within managed care there is movement from specialty behavioral health plans to mainstream managed care. The question is whether we can sustain the focus on quality of care for those most in need during this transition. We do not yet have national standards for the quality of care for people with serious mental illness, so the transition away from expert leadership is risky. We failed to maintain focus during an earlier era of deinstitutionalization; we must not make this mistake again.

<u>Children's mental health care.</u> Mental health problems have been called "the major chronic diseases of childhood." Mental illness usually emerges before young people enter high school, but the average lag to treatment is 9 years. Only about a quarter of children with mental health problems see a mental health professional, and often not enough care is delivered to make a difference. At the same time, we are scandalized by reports showing increased levels of psychiatric medication use among children, often with no adequate counseling to supplement or as alternative to medications. We see the results of insufficient mental health care in school failure and youth suicide. How do we do better?

While the gaps in children's mental health care are huge there is also reason for hope. In part, this is because we know more about what works, and what doesn't. We must start applying this knowledge. The timing is right if we act as we should; there are opportunities in healthcare

reform and in calls to improve school mental health care. But like improvements to mental health care in primary care, improvement will not occur unless steps like these are taken:

- Make screening for and treating maternal depression standard for the first two years after birth. Maternal depression is prevalent, treatable, and can lead to big problems in development of the young child if left untreated. Treating mom's depression reduces levels of mental health problems for her children by half!
- Help pediatric practices and child mental health programs to provide holistic care. Noted columnist David Brooks—scarcely a bleeding heart liberal—has written persuasively of the problem of children growing up without the ability to "self-regulate"—to manage themselves and their own behavior. These skills can be taught –but only if we begin early by providing structured support to young parents. To do this, we need to be able to:
  - o Begin therapy for children without a specific diagnosis—to reduce the chance that a serious diagnosis will be given later.
  - O Allow comprehensive pediatric practices and child mental health programs to bill for parent training and support for behavior management—to reduce the use of major medication use after the behavior has gotten worse
  - O Reimburse and support team based care in pediatrics including physician attendance at team meetings with families
  - Reimburse pediatric and child mental health programs for care coordination with schools and other agencies; care coordination may be more effective and cost-effective than layering on additional treatments.
- Put better performance standards in place for child mental health programs. Right now national standards are limited to ADHD and follow up after hospitalization. Adolescent depression indicators are being developed but are not yet approved or used. What doesn't get measured in health care often doesn't get done.
- Do school mental health right. The President's proposals following the tragedy in Newtown include significant expansion of school mental health. Done right, this could be a significant benefit. But we now know more about what is effective, and what isn't. Expanded programs should only use proven approaches, such as peerassisted learning, and cognitive behavioral interventions for trauma, adapted for schools. Each of these approaches has been linked to improving educational outcomes.

Develop a national approach for effective early treatment of psychotic illness. Our nation's approach to helping people with psychotic illnesses like schizophrenia is shameful. Usually, young people slip into psychotic illnesses for several years while they—or their families—get no help. When they have a "first psychotic break," they usually are briefly hospitalized. Almost always, medications take the worst of the symptoms away—within days or weeks. So then they are discharged with a referral to care and maybe a recommendation of a support group. This is woefully, stupidly deficient. Having symptoms reduced is not a cure. When people feel better, and especially since the drugs have significant side effects, they often stop taking them. Relapse is likely. Usually the second break is worse. And then the revolving door begins. Often after decades people figure out how to manage their illness, but by then they are often on permanent disability status, unemployed, and in terrible health.

Some have suggested that the solution to this problem is in going backward—not forward—to days when stays in mental hospitals were measured in months and years. This is idiotic. There is no research to suggest it is effective. It is terribly expensive. Hospitals cannot be run (as the old asylums were) on unpaid patient labor. And a civilized society cannot detain people on a vague hope they will get better. So we will not turn the clock back on mental health care. But we do need a modern approach to care for people with psychotic disorders, one that replaces both the asylum and the revolving door with continuous team treatment like that we provide for people with chronic medical problems. Teams delivering First Episode Psychosis (FEP) care have figured out how to do this work. It is person-centered, family driven, collaborative and recovery oriented. Staying in school or work is encouraged—though adaptations may be needed. It is time to implement this approach, as both Australia and Great Britain have done. We need not lag behind other nations in this area. Our country needs to make modest investments now to develop FEP teams so that families anywhere in the state struggling with a young adult who is slipping away from sanity can get good care reasonably close to home. The Committee's attention to this issue could have an enormous positive effect.

Lifelong disability for people with mental illness is usually unnecessary. While many of the worst outcomes of serious mental illness (e.g. homelessness, comorbid medical illness, incarceration) are receiving increased attention, we are failing systematically to help people escape poverty and disability. In effective supported employment approaches such as Individual Placement with Supports (IPS) a majority of adults with serious mental illness find a job. But we generally fail to use this effective program. The nation's Vocational Rehabilitation (VR) system is focused on employment for people with disabilities, but it is limited in scope and flawed in its approach to helping people with mental illness. Most people with serious mental illness never get VR services, and among those who do, outcomes are worse than for other groups of people with disabilities. Most VR programs do not use IPS systematically. Meanwhile, Medicaid does not pay for key components of IPS. Because of these cracks between systems, an effective approach is usually not made available, and the employment rate among people with serious mental illness who are receiving care is, scandalously, about 15%.

Supplemental Security Income (SSI) and, for those who become disabled after working, Social Security Disability Income (SSDI) are invaluable lifelines for people with serious disability including serious mental illness. But many people with mental illness on SSDI and SSI want to work. And most could work—at the very least in part-time private sector employment—if IPS was available and if disability was not an "all or nothing" program.

I would like to bring to the Committee's attention an innovative program established by New York State and the Social Security Administration to address this problem. It takes advantage of Ticket To Work—a well-intended back-to-work incentive program that has never reached its potential, largely because of its complexity. The New York State Office of Mental Health (OMH) in collaboration with the New York Department of Labor and other state agencies serving people with disabilities developed a comprehensive employment system for people with serious mental illness and other disabilities. Key components include: 1) education and counseling on benefits (such as how to maintain Medicaid coverage while working, and how to take advantage of complex Social Security work incentives); 2) an integrated information system that links people to and is built onto the Department of Labor's workforce system; and 3) a

statewide network of IPS services delivered through OMH Personalized Recovery Oriented Services (PROS) programs. Via a unique partnership agreement, the Social Security Administration has designated this system including all participating consumers and providers as a Ticket To Work Employment Network. This arrangement is the most systematic statewide approach to employment services and to fully using available benefits to support productivity instead of poverty and disability.

I urge the Committee's attention to the costs and consequences of unnecessary disability for people with serious mental illness, in particular to:

- Assuring that Vocational Rehabilitation and Medicaid figure out how to make effective Individual Placement with Supports services available to all people with serious mental illness who want work instead of poverty, and
- How the Social Security/New York partnership can be implemented in other states.

Suicide prevention: Now is the time to act. We are dismayed by reports that deaths by suicide in the Armed Forces last year exceeded other combat deaths. This concern is surely justified. Yet this is but the tip of the iceberg; twice as many American lives are lost to suicide in the average week than to military suicide in a year. Suicide, which is the tenth leading cause of death —and the third leading cause of death among young adults—receives a relatively small investment in terms of research and programming than other public health problems of its magnitude. We can and we must do more.

The administration, to its credit, has begun to focus on suicide prevention. In 2010, Secretaries Sebelius and Gates launched the Action Alliance on Suicide Prevention, a public-private partnership co-chaired by Army Secretary John McHugh and former Senator Gordon Smith. With support from the Action Alliance, Surgeon General Regina Benjamin has released a comprehensive update of the National Strategy on Suicide Prevention, originally released in 2001. Yet more action is needed. Suicide prevention activities are scattered and thin. Outside the Department of Defense, the only national efforts are the National Suicide Prevention Lifeline (1-800-273-TALK), a technical assistance center, and the small network of youth and college prevention programs funded by the Substance Abuse and Mental Health Services Administration under the Garrett Lee Smith Memorial Youth Suicide Prevention Act.

It is time to do more to fight this needless and often preventable form of death. It is claiming the lives of students, soldiers, veterans, and Americans of every age and background. Congressional action would help advance this cause, as it did with passage of the Garrett Lee Smith Act. The Action Alliance is focusing integrating state-of the-science suicide prevention practices into initiatives under the Affordable Care Act. We assess that current clinical practices in the U.S. are one to two decades behind the research, which demonstrates that effective care, what we call "suicide care," targeted to patients who are at risk, can significantly improve their prognosis. The Affordable Care Act offers numerous opportunities to incorporate best and effective practices into preventive services offered through Medicare and Medicaid, into electronic health records, and into other reform initiatives.

Suicide prevention is an area where small amounts of money can make a difference. The Action Alliance has the potential to bend the curve on suicide, but it is funded this year via a time-limited grant from SAMHSA. Similarly, the Nation's network of certified crisis lines, although linked together by the SAMHSA funded Lifeline project, is mostly funded by state and local-level grants and philanthropy, yet it is projected to respond to a million callers this year, a large proportion of whom are in utter desperation and on the threshold of their own death. Research has conclusively shown that these crisis lines are effective and are performing as an indispensable part of the nation's health care system, yet they receive no federal support. The Committee's attention could help assure that other federal agencies do more to help, that the National Action Alliance for Suicide Prevention is sustained and that the national network of crisis lines is strengthened. These steps would be life-saving.

Conclusion. We thank the Committee again for focusing on mental health needs and opportunities, and we hope our suggestions are relevant and helpful. Some of the issues I discuss do not necessarily suggest easy fixes. But mental health concerns are coming out of the shadows, at a time of major change in health and mental health care. Now is the time to get it right. We face major opportunities to improve health care for millions of Americans, but these are opportunities that can easily be missed. Similarly, we cannot allow what remains of the nation's mental health system for people with the most serious disorders to be dissipated. In an earlier, failed era of deinstitutionalization, patients were dumped into unprepared communities. This is not the time to dump them again, into "mainstream" arrangements without adequate protections and accountabilities. Fixing the mental health system requires more than gun control. And it is possible.