

February 3, 2016

The Honorable Lamar Alexander
Chairman
U.S. Senate Committee on Health, Education, Labor, and Pensions
455 Dirksen Office Building
Washington, DC 20510

The Honorable Patty Murray
Ranking Member
U.S. Senate Committee on Health, Education, Labor, and Pensions
154 Russell Senate Office Building
Washington, D.C. 20510

RE: Full Committee Hearing: Improving the Federal Response to Challenges
in Mental Health Care in America

Dear Chairman Alexander and Ranking Member Murray:

The undersigned mental health, disability and civil rights organizations submit this letter for the record following the HELP Committee's January 20, 2016 hearing, *Improving the Federal Response to Challenges in Mental Health Care in America*. We are national organizations that work to promote equal opportunities for individuals with mental disabilities in all aspects of life, including health care, housing, community living, employment, education, and other areas.

We applaud the Committee's interest in and concern about the mental health service systems. As the hearing highlighted, many individuals are poorly served by the mental health service systems. Services that individuals with psychiatric disabilities need are far too often unavailable to them.

We are concerned, however, about the hearing's focus on expanding psychiatric institutions, rather than the intensive community-based services that are in woefully short supply across the country. These community-based services have tremendously successful outcomes, including for people with the most significant psychiatric disabilities.

The Primary Challenge is Insufficient Availability of Community Services

Over the years, many reports – including the 1999 Surgeon General's *Report on Mental Health*; President Bush's 2003 *New Freedom Commission on Mental Health* report; and the HELP Committee's own 2013 report, *Separate and Unequal: States Fail to Fulfill the Community Living Promise of the Americans with Disabilities Act*, have recognized that the mental health system is failing individuals because we have not sufficiently invested in ensuring access to basic community-based services. As the National Association of State Mental Health Program Directors has noted, “. . . even people with the most severe mental illnesses and active substance

use disorders can live successfully in apartments of their own when provided with comprehensive, appropriate, and voluntary services.”¹

The Medicaid program funds a well-established set of intensive community services with proven outcomes, including supportive housing, mobile crisis services, peer support services, supported employment and a variety of other services. Yet demand for these services far outstrips supply in every state. And as Ranking Member Murray pointed out, many places have no services available. As your Committee pointed out in 2013, state Medicaid programs have continued to over rely on institutions at the expense of community services, in contravention of the ADA’s integration mandate and the Supreme Court’s *Olmstead* decision.² Ironically, these gaps in community services result in costly spending on psychiatric hospitals, jails, emergency rooms, and shelters. Much of this spending could be avoided—and individuals’ lives substantially improved—if sufficient community services were available.

Repealing Medicaid’s IMD Rule Will Not Fix the Mental Health System

As a number of the witnesses noted, locating and accessing psychiatric hospital beds is often challenging. The immediate solution, however, is not to build more inpatient beds, but instead to build a well-functioning community system that has the capacity to resolve crises without hospitalization, that addresses mental health needs early to prevent needless hospitalizations, and that enables shorter lengths of stay in hospitals. States have achieved immediate and significant reductions in hospital admissions and incarceration by expanding intensive community-based services such as mobile crisis teams, supported housing, and family and peer support. Federal investment in expansions of these services would reduce admissions, facilitate timely discharges, and free up hospital beds. Absent investment in these services, individuals will continue to cycle in and out of hospitals, at great expense to service systems and to individuals’ lives.

As noted by Dr. Jess Jamieson, former Director of State Hospitals in Washington State:

*When I was running the State hospitals in Washington, we were right in the middle of this controversy...boarding patients in the ERs waiting for a bed. My hospitals were full, so the prevailing attitude was we needed more beds. This is not the solution!! What I needed was a stronger community-based system to divert patients from inpatient hospitalizations and the community resources to discharge my patients who were ready for community placement, thus opening up a bed for those patients who needed hospitalization. The problem was, the community system was under funded and lacked resources.*³

A great deal of work, including on the part of the federal government under both Republican and Democratic administrations, has gone into a national effort to shift resources away from needless

¹ NASMHPD Policy Brief, *Affordable Housing: The Role of the Public Behavioral Health System* (Oct. 2011), at 9, http://www.nasmhpd.org/sites/default/files/PolicyBrief_Housing2011.pdf.

² Senate HELP Committee, *Separate and Unequal: States Fail to Fulfill the Community Living Promise of the Americans with Disabilities Act* (July 18, 2013).

³ <http://www.openminds.com/market-intelligence/executive-briefings/take-something-put-something.htm>.

institutionalization and begin to rebuild community mental health service systems that have experienced repeated funding cuts, creating the promise of better lives for individuals with psychiatric disabilities. Moreover, both the U.S. Department of Justice (DOJ) and private litigants have entered into *Olmstead* settlement agreements across the country requiring states to offer sufficient supported housing, mobile crisis services, supported employment, peer support, and other services to avoid needless institutionalization in state psychiatric hospitals, psychiatric nursing facilities, adult homes, and other institutional settings.⁴ In all of these cases, states have implicitly conceded or courts have found that the development of community services for large numbers of individuals with psychiatric disabilities was needed to avoid widespread inappropriate institutionalization. This Committee should not entertain measures that would send us backward.

Finally, we note that federal Medicaid reimbursement is available for psychiatric hospital care in general hospitals. As the hearing witnesses emphasized, integration of mental health and medical care is extremely important. People with significant psychiatric disabilities have high rates of diabetes, heart disease, cancer, stroke, and pulmonary disease, and they tend to die at a much earlier age than the general population. These physical health problems may be exacerbated by obesity, smoking, substance use, and side effects of psychiatric medications. General hospitals with psychiatric units are well positioned not only to address a mental health crisis, but to treat the “whole person,” including co-occurring and interrelated physical health issues. Incentivizing inpatient psychiatric care in stand-alone psychiatric institutions that are not fully equipped to address physical health care needs moves the system further away from integrated care.⁵

HIPAA does not bar the sharing of information when a person lacks capacity to consent or object

The story that Ms. Blake related at the hearing—of her decision not to communicate with the family of a young man who was unconscious in the emergency room because of her belief that HIPAA barred her from doing so—is a common one. However, that belief is simply wrong. HIPAA allows providers to disclose information to families in exactly those circumstances. As HHS stated last year in guidance: “Where a patient [. . .] is incapacitated, a health care provider may share the patient’s information with family, friends, or others involved in the patient’s care

⁴ See, e.g., *United States v. Georgia* (state psychiatric hospitals; settlement approved 2010); *United States v. Delaware* (state psychiatric hospital and private IMDs; settlement approved 2011); *United States v. North Carolina* (privately operated adult care homes for individuals with psychiatric disabilities; settlement approved 2012); *United States v. New Hampshire* (state psychiatric hospital and state nursing home for individuals with psychiatric disabilities; settlement approved 2014); *United States v. New York* (adult homes for individuals with psychiatric disabilities; settlement approved 2014). See also *Disability Rights New Jersey v. Velez* (state psychiatric hospitals; settlement approved 2009); *Williams v. Quinn* (privately operated IMD nursing homes in Illinois; settlement approved 2010); *Office of Protection and Advocacy v. Connecticut* (privately operated nursing homes; settlement approved 2014); *Katie A. v. Bonta* (California foster care children with mental health needs in or at risk of placement in institutions; settlement approved 2011); *T.R. v. Quigley* (Washington State children with mental health needs in or at risk of placement in institutions; settlement approved 2013).

⁵ Given the dramatic effects that it may have on mental health service systems, any change to the rule should occur through the regulatory process by which CMS has begun to consider possible modifications; this process is informed by all relevant stakeholders and conducted by an agency with significant expertise.

or payment for care, as long as the health care provider determines, based on professional judgment, that doing so is in the best interests of the patient.” Ms. Blake’s testimony demonstrates the need to educate providers concerning HIPAA’s requirements, not the need to carve out exceptions to HIPAA.

SAMHSA Plays an Important Role

The Substance Abuse and Mental Health Services Administration, which was discussed several times during the hearing, has played an extremely important role in promoting the development of these effective, recovery-oriented community service approaches, including a variety of critical peer support services such as those described by the hearing witness, Mr. Rahim. SAMHSA is only one part of the Federal Government’s response to people with psychiatric disabilities, a fundamentally important part that should be maintained. Giving SAMHSA more authority to coordinate work across federal agencies addressing mental health issues would be beneficial; creating new levels of bureaucracy above SAMHSA would not. We urge the Committee to support SAMHSA’s important work.

Thank you,

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