The Judge David L.
BAZELON CENTER
for Mental Health Law
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April 2, 2014

Hon. Fred Upton
Chair, Committee on Energy and Commerce
2183 Rayburn House Office Bldg.
Washington, D.C. 20515

Hon. Henry Waxman
Ranking Member, Committee on Energy and Commerce
2204 Rayburn House Office Bldg.
Washington, DC 20515

Hon. Joe Pitts
Chair, Subcommittee on Health
420 Cannon House Office Bldg.
Washington, DC 20515

Hon. Frank Pallone
Ranking Member, Subcommittee on Health
237 Cannon House Office Bldg.
Washington, DC 20515

Re: April 3, 2014 Hearing on H.R. 3717, Helping Families in Mental Health Crisis Act

Dear Chair Upton, Ranking Member Waxman, Chair Pitts, and Ranking Member Pallone:

The Bazelon Center for Mental Health Law submits the following testimony for the record of the above-referenced hearing. Founded in 1972, the Bazelon Center is a national non-profit legal advocacy organization that represents individuals with mental disabilities. Through litigation, legislative and administrative advocacy, education and training, the Center promotes equal opportunities for individuals with mental disabilities in all aspects of life, including education, health care, housing, employment, community living, voting, and family rights.

The Center opposes H.R. 3717 for the reasons outlined below.

1. **The bill eliminates critical legal advocacy on behalf of individuals with psychiatric disabilities**

Recognizing that people with psychiatric disabilities are at greatly elevated risk of abuse, neglect, exploitation, and other violations of their rights under Federal and state laws, in 1986 Congress created the Protection and Advocacy for Individuals with Mental Illness Program (PAIMI). Nationwide, PAIMI programs have provided essential legal representation and advocacy for these vulnerable individuals. At the inception of PAIMI programs, substantial numbers of people with mental illnesses lived in psychiatric hospitals and nursing homes that were rife with abuses. While abuses continue to occur within these settings, states' PAIMI programs have intervened to stop such mistreatment, have investigated abuse, neglect and deaths in psychiatric facilities and obtained important policy and practice changes to keep residents safe, and they have brought significant improvements in the living conditions of facility residents.

PAIMI programs have also done important legal advocacy to promote community integration of individuals with mental illnesses, affording them the opportunity to have normal lives and to receive the services they need to succeed and be full participants in their communities. The Americans with Disabilities Act (ADA) and the Supreme Court's *Olmstead* decision provide that the needless institutionalization of individuals with disabilities is a form of discrimination. As the Supreme Court has observed, needless institutionalization deprives individuals of opportunities to exercise basic choices and to be a meaningful part of their communities, and also perpetuates unfounded assumptions that people with disabilities are incapable or unworthy of participating in society. As a result of the ADA and other federal and state laws, significant numbers of individuals with mental illnesses have been able to move from institutional warehouses and to the mainstream of their communities where they live successfully with supportive services. Accordingly, while remaining attentive to the wellbeing of individuals who remain segregated in institutions, PAIMI programs now also play a crucial role in helping people avoid needless institutionalization as well as protecting them from discrimination in their communities.

Today, most people with serious mental illnesses do not live in hospitals or nursing homes and, contrary to what news media attention might suggest, by far, most live quietly and peaceably with their families or in a variety of community settings. These individuals are still vulnerable to abuse and rights violations, but of a different type than was common when the PAIMI programs were instituted. The problems they commonly face today include accessing health and mental health services and discrimination in housing, education, employment, voting, and parental rights. Nationwide, PAIMI programs have not only provided critical legal representation for individuals with respect to these issues, but they have been leading drivers of improvements in states' service systems, often in collaboration with leadership within states' mental health and human service agencies.

H.R. 3717 would return us to the conditions that Congress intended the PAIMI program to prevent. It would cut PAIMI funds by 85%, eviscerating the primary system of legal advocacy for individuals with psychiatric disabilities, leaving them without means to enforce their legal protections from discrimination in these key areas of life. It would also eliminate all PAIMI legal advocacy except individual advocacy relating to abuse and neglect. Thus, PAIMI programs could no longer advocate for children to receive school-based mental health services they need to receive an appropriate education, for adults with mental illnesses to secure the accommodations they need to stay employed or to obtain desperately needed housing, or for children to receive the mental health services they need to remain with their families rather than being institutionalized.

In effectively eliminating PAIMI programs, the bill essentially undermines its own intent. H.R. 3717 recognizes that the patchwork of federal programs and requirements (overlaying a similar patchwork at the state level) has made it very difficult for individuals with serious mental illness to access the services they need, resulting in adverse outcomes such as homelessness, hospitalization or incarceration. Through their advocacy to reform public systems affecting individuals with mental illnesses, PAIMI programs play a critical role in promoting timely and effective access to the very services that can reduce vulnerabilities to these outcomes. Limiting PAIMI programs' capacities to do little beyond investigating abuse and neglect would remove a critical agent in promoting reforms in states' systems to improve early access to services and to expand housing, employment, and educational opportunities—not only enabling individuals to have better lives but also reducing risks.

2. The bill redirects federal money from innovative programs to involuntary outpatient commitment, which is expensive and ineffective

Public mental health systems have been heavily reliant upon legal interventions when individuals with serious mental illnesses are at immediate risk of danger to themselves or others, or when their failure to adhere to treatment requirements has resulted in repeated hospital admissions, at great cost to states. At one time, civil commitment allowed states to consign people with mental illness to psychiatric hospitals—often for decades—in part, because effective treatments for disorders such as schizophrenia or bipolar disorder did not exist. As was affirmed by the Surgeon General's Report on Mental Health (1999), it is no longer the case that effective treatments are lacking; what is lacking is appropriate *access* to those services, resulting in preventable emergencies and hospital admissions.

Resources in community mental health programs have been unavailable to many thousands of individuals who need them. Significant numbers of people with serious mental illnesses enter the criminal justice system not because of a lack of knowledge about how to help them, but because basic mental health care is unavailable and because in the absence of housing or employment, these individuals are at risk of committing "crimes of survival"—panhandling, shoplifting, loitering, and so on. In addition, for a variety of reasons, co-occurring substance abuse among this population is widespread, adding to their vulnerabilities to arrest or crisis.

Nationwide, public mental health providers have come to see involvement by the police or the courts as routine and, perhaps, inevitable. This perspective has over the years contributed to an environment in which people who are under-served by public mental health programs deteriorate and wind up incarcerated or civilly committed, as mental health systems passively observe from the sidelines. The overall situation offers little incentive for mental health programs to innovate and to engage at-risk individuals voluntarily earlier on; instead, it allows service systems to do little and to rely on the courts to intervene as crises occur (through court-ordered treatment). It also allows these programs to transfer with impunity responsibility for ostensibly hard-to-serve individuals to the criminal justice system. This not only poorly serves individuals, but also promotes reliance on expensive, high-end services and the spending of scarce resources on court systems rather than on needed services. The reliance on the courts for mental health care (or on the police or criminal justice system) should signal problems in mental health programs and their failure to provide effective, innovative services to at-risk individuals.

The bill's provisions to fund demonstration programs relating to "Assisted Outpatient Treatment" (AOT) represent another step towards using the courts as a late-stage intervention, rather than addressing the underlying problem of limitations in community resources. This would undermine the development of effective mental health service systems.

The vast majority of states already have some form of AOT in their mental health laws. Notwithstanding aggressive advocacy to promote AOT—often capitalizing upon tragedies perpetrated by individuals who would not qualify for AOT—in practice, it is rarely used in most states that have adopted it. Providing federal incentives for broader use of AOT would have the effect of encouraging mental health programs to further incorporate the legal system into their service approaches. This is not good health care.

The perceived need for AOT is highly related to the availability of community-based services. AOT has been very controversial. Even where it has been shown to have positive outcomes, the evidence suggests that these outcomes are due to individuals receiving intensive services that were previously unavailable to them—and that could be provided on a voluntary basis—rather than due to a court mandating these services. The two systematic reviews of the empirical literature on AOT both reached the same conclusion: there is no evidence that a court order makes any difference.

Some AOT advocates assert that court intervention, in itself, is a useful tool because of the "black robe effect"—the notion that a judge ordering an individual to comply with treatment has some palpable impact. On its face, this argument is flawed because these same advocates argue that individuals appropriate for AOT have neurological impairments that limit their understanding of their mental illness and its impact. Moreover, such individuals invariably have been in front of many black robes before, for civil commitment and, often, for criminal hearings. Why an AOT black robe would make any difference is wholly unclear.

What AOT does do, if sufficient monitoring resources are appropriated (which has not occurred in the vast majority of states with AOT due to the extraordinary expense) is increase scrutiny of the mental health service system. But such scrutiny can be accomplished other ways, and using AOT to pressure accountability within public mental health is mis-directed. An appropriately structured system of community services can reduce the perceived need for court intervention. In an ongoing settlement agreement between the U.S. Department of Justice and the State of Delaware, for example, there have been dramatic enhancements in community mental health services, including assertive community treatment, peer supports, mobile crisis services, and supported housing. Since implementation of the settlement began, reliance on civil commitment for hospital care has been reduced by half and on outpatient commitment (AOT) has been reduced by 60%. This outcome highlights the interdependence of ineffective, underfunded community systems and the reliance upon court-ordered treatment.

H.R.3717 weds federal funding for innovation with the very approach that stifles innovation. Public mental health systems' over-reliance on court interventions has had the effect of reducing their focus on innovative engagement of individuals through good, timely clinical and peer services and engagement with families. The bill would further this problem, prohibiting states from receiving federal mental health block grant funds that are used to support innovative services unless they are using involuntary, court-ordered outpatient commitment—a controversial and costly approach that runs counter to recovery, independence and choice. It would also significantly reduce funding for important and innovative community-based services in favor of involuntary treatment.

There is no evidence that AOT improves public safety. People who are a danger to themselves or others due to their mental disability may, under current law, be hospitalized and held against their will. But, when safety is not threatened, voluntary treatment is the best approach, not only because it provides the greatest protection of and respect for an individual, but also because it more often yields long term engagement in treatment. Experts believe that identifying and applying interventions that avoid mental health crises in the first place would better serve the community.[1]

People with psychiatric disabilities are no more prone to violence than the general population.[2] Further, violent behaviors in people with and without mental illnesses are "more common when there's also the presence of other risk factors" including abuse, drug or alcohol dependence, and recent stressors such as being a crime victim or losing a job.[3] Thus, if public safety is the goal, our focus should be on ensuring that effective, voluntary treatment, is widely available to everyone.

3. The bill reduces privacy protections for individuals with psychiatric disabilities

The bill would strip away privacy protections under the Health Insurance Portability and Accountability Act from individuals with psychiatric disabilities and provide them with lesser privacy safeguards than everyone else. It would give broad latitude to family members and service providers to override the wishes of individuals with psychiatric disabilities to keep information about their mental health treatment confidential, and thus would deter many individuals from seeking the help that they need. Moreover, HIPAA already permits providers to disclose information to family members in appropriate circumstances, including when there is a good faith belief that disclosure "is necessary to prevent or lessen a serious and imminent threat to the health or safety of the patient or others," when the individual does not have capacity to agree or object to the sharing of information, in emergency circumstances, or when the individual consents. While it would be useful for providers to work with individuals on engaging their families, H.R. 3717 does nothing to promote that or to address the underlying problem, which is not HIPAA, but rather providers' reluctance to engage with families.

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[1] *See, e.g.,* Dr. Michael Rowe, *Alternatives to Outpatient Commitment*, 41 J. Amer. Acad. of Psychiatry and the Law 332, 335-36 (Sept. 1, 2013), http://www.jaapl.org/content/41/3/332.full.pdf+html (describing the studies).

[2] Jerry Zremski, *Better Care For Mentally Ill Won't be Enough, Experts Say*, BUFFALO NEWS (Dec. 16, 2012), http://www.buffalonews.com/apps/pbcs.dll/article?AID=/20121215/CITYANDREGION/121219410/1010.

[3] Eric Elbogen and Sally C. Johnson, *Mental Illness by Itself Does Not Predict Future Violent Behavior, Study Finds*, SCIENCE DAILY (Feb. 3, 2009), http://www.sciencedaily.com/releases/2009/02/090202174814.htm.

4. The bill would increase needless institutionalization

The bill would fundamentally change the Medicaid program by allowing states to obtain federal Medicaid reimbursement for acute inpatient psychiatric hospital services for non-elderly adults. These services have been the responsibility of states since before Medicaid was enacted almost fifty years ago and, through exclusion of federal funds to pay for services in Institutions of Mental Diseases (IMDs), Congress determined that it should remain so. The exclusion of federal funds for IMD services has been an important means of promoting community integration. Federal reimbursement for IMD services would result in large numbers of individuals with psychiatric disabilities being served needlessly in hospitals, driving mental health systems backward. In addition, it would cost the federal government billions of dollars.

Allowing federal Medicaid payments for IMD services would reward those states that have done the least to develop community services and that over-rely on psychiatric hospitals. For individuals covered by states' traditional Medicaid plans, the coverage of services within IMDs would provide significant federal funds for what had always been a state responsibility. In states that have pursued the Affordable Care Act's Medicaid expansion, this state responsibility would now become essentially 100% federally funded for individuals in the expansion population.

The Medicaid Emergency Psychiatric Demonstration Program of the ACA is already examining the impact of Medicaid reimbursement for acute psychiatric hospitalization. The intent of Section 2707 of the ACA is to examine whether eliminating the prohibition against payments to IMDs for services rendered to Medicaid recipients aged 21 to 64 improves psychiatric care for people with mental illness and lowers states' Medicaid program costs. Absent the outcomes of this demonstration program, it is premature to implement a change in the IMD exclusion, which would not only be costly, but which would also use substantial federal funds to incentivize institutionalization.

Medicaid already covers psychiatric care in a general hospital. There is an increasing recognition that mental health is a part of overall health, and that mental health care should be a part of overall health care. People with serious mental illnesses 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. (http://grants.nih.gov/grants/guide/rfa-files/RFA-MH-14-060.html) 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 to not only address a mental health crisis, but to treat the "whole person," including co-occurring and interrelated physical health issues. Medicaid already pays for inpatient psychiatric care in these settings, and thus, a change in Medicaid law is not required to encourage comprehensive hospital care. Incentivizing inpatient psychiatric care in settings that are not fully equipped to address the mental and physical health care needs of the whole person moves the system further away from integrated care. Furthermore, this effect is inconsistent with the Bill's provisions that incorporate the Excellence in Mental Health Act which, among other goals, seeks to closely integrate primary care with mental health care in outpatient settings.

Thank you for the opportunity to submit these comments.

Sincerely,

Robert Bernstein

Robert Bernstein

President and CEO