TIM MURPHY
18TH DISTRICT, PENNSYLVANIA

COMMITTEE ON ENERGY AND COMMERCE
CHAIR, OVERSIGHT AND INVESTIGATIONS
ENVIRONMENT AND ECONOMY
HEALTH

CO-CHAIR, STEEL CAUCUS
CO-CHAIR, MENTAL HEALTH CAUCUS

WEBSITE: murphy.house.gov

Congress of the United States
House of Representatives
Washington, DC 20515

May 6, 2014

The Honorable Fred Upton
Chairman
Committee on Energy and Commerce
U.S. House of Representatives
Washington, DC 20515

The Honorable Henry Waxman
Ranking Member
Committee on Energy and Commerce
U.S. House of Representatives
Washington, DC 20515

Dear Chairman Upton and Ranking Member Waxman,

I write to provide insight and further background on a letter you recently received from a group of disability rights organizations regarding my Helping Families in Mental Health Crisis Act (H.R. 3717).

The letter contains numerous inaccuracies and misleading statements designed to stoke fear about the legislation, and I appreciate the opportunity to set the record straight.

The bipartisan Helping Families in Mental Health Crisis Act is the result of a year-long review conducted in the Oversight & Investigations Subcommittee examining the nation's broken mental health system and why those who are in desperate need of acute psychiatric care are simply not being served.

From multiple public forums, congressional hearings, investigative work, and in interviews with providers, families, and patients, three key reasons were repeatedly cited as to why those with serious mental illness (SMI) often are just as likely to end up homeless, in prison, or dead by suicide as in a meaningful healthcare treatment setting.

First, families are often shut out from helping a loved one experiencing an acute mental health crisis due to confusing federal standards on what a caregiver can be told about their loved one's illness, and what information medical providers can accept from a caregiver.

Second, there exists a significant lack of inpatient treatment and outpatient treatment options.

Third, current federal resources are not targeted towards the hardest-to-treat patients, and in some cases, are actually blocking them from accessing medical care. For instance, the Substance Abuse and Mental Health Services Administration provides grants to legal advocates and anti-psychiatry activists working to stop care instead of funding needed medical treatment.

☐ 2332 RAYBURN HOUSE OFFICE BUILDING
WASHINGTON, DC 20515
(202) 225-2301
FAX: (202) 225-1844

☐ 504 WASHINGTON ROAD
PITTSBURGH, PA 15228
(412) 344-5583
FAX: (412) 429-5092

☐ 2040 FREDERICKSON PLACE
ROUTE 136
GREENSBURG, PA 15601
(724) 850-7312
FAX: (724) 850-7315

advocates and anti-psychiatry activists working to stop care instead of funding needed medical treatment.

To be clear, nothing in the Helping Families in Mental Health Crisis Act undermines civil rights or jeopardizes the safety of persons with mental illness. In fact, the legislation helps more persons with mental illness live in a community-based setting because the bill offers greater choice, supportive services, and effective treatment options with a focus on recovery. It reinforces a basic civil and human right by providing access to medical treatment to improve the quality of life and help those with serious mental illness recover.

Scrutinizing SAMSHA's "Programs of Regional and National Significance (PRNS)"
Since 2002, the Substance Abuse and Mental Health Services Administration (SAMHSA) has operated without congressional authorization. As a result of having not been scrutinized by Congress for more than a decade, SAMHSA lacks mission focus, has deviated from congressional intent, and spent taxpayer dollars on programs that at best are of dubious quality and effectiveness, and at worst are impeding care from being delivered to the most vulnerable patient population.

The letter you received misleadingly suggests the Programs of Regional and National Significance (PRNS) would "be arbitrarily capped at $150 million, sharply below the $378 million currently authorized." This is untrue. H.R. 3717 sets an authorization level for PRNS after careful scrutiny. The new amount promotes greater transparency, reflects individual grantee effectiveness, and restores congressional intent for the program.

With its 26 different grant programs, PRNS has become a catchall for any idea in the behavioral health space without any overarching direction or coordination, let alone measure of effectiveness. PRNS has no fewer than six suicide prevention programs; none have been audited or reviewed for effectiveness. In part through PRNS, SAMHSA operates three grant programs targeted at homelessness — in addition to the other 23 homelessness programs run by federal agencies.[1] Again, there is no measureable standard by which these programs have been judged. The same goes for the $25 million given to Safe Schools Healthy Students (SS/HS) program — despite two of three SS/HS collaborators, the Department of Education and the Department of Justice, having terminated their participation!

While any one of these aforementioned programs may indeed be worthwhile and effective, the mere duplication and changes in federal priorities demand a thorough review by the authorizing committees of Congress to determine if they are achieving intended outcomes. Furthermore, programs designed to treat persons with mental illness, arguably one of the most vulnerable patient populations, should be held to a higher clinical, evidence-based standard. H.R. 3717 focuses resources on innovative programs while requiring the collection of detailed information regarding the efficacy of grants so future funding determinations are made on an extensive evidence base. And, the

[1] "Homelessness: Fragmentation and Overlap in Programs Highlight the Need to Identify, Assess, and Reduce Inefficiencies," Government Accountability Office. May 10, 2012.

"evidence" of effectiveness required under the legislation is of a higher scientific standard, one that identifies the strengths and values of programs in a manner that can be replicated. Those programs and grants that fail to meet the scientific standards of effectiveness, however, will be reviewed by the Assistant Secretary for Mental Health and Substance Use Disorders and phased out if appropriate.

It is important to note that the President's budget has never requested full funding for PRNS, nor has Congress appropriated more than $299M for PRNS (FY2014). That $299M appropriations figure included several programs that are separately re-authorized under H.R. 3717, including the National Child Traumatic Stress Network ($50M) and Garrett Lee Smith Youth Suicide Prevention Program ($55M).

Access to Critical Inpatient Treatment and Community-Based Care
For the last fifty years, the federal government has reimbursed states for approximately half of the cost for inpatient medical care, *unless that patient has a psychiatric illness.*

Persons with serious mental illness needing acute psychiatric care are routinely blocked from inpatient facilities while those with private insurance are not. The federal "Institutions of Mental Disease" (IMD) exclusion essentially prohibits Medicaid beneficiaries between the ages of 21 and 64 — no matter how sick they may be — from receiving mental health or substance abuse care in a free-standing private or state psychiatric hospital with more than 16 beds. To deny inpatient treatment to a Medicaid beneficiary because they have a mental illness is cruel and inhumane. H.R. 3717 eliminates this discriminatory policy and ensures mental health parity exists for persons on Medicaid.

Many patients experiencing acute or prolonged psychiatric episodes need medical attention, but there exists a severe shortage of psychiatric bed space available for medical stabilization.

During a March 26, 2014 Oversight and Investigations Subcommittee hearing on the shortage of psychiatric beds, clinicians, parents, and law enforcement professionals testified about how many hospitals are forced to "board" patients in ERs on gurneys — even in hospital hallways — until a bed becomes available. Patients are forced to remain in four-point physical restraints in a bed for hours, days, or weeks until a psychiatric bed opens up elsewhere. While boarded in an emergency room instead of being treated in a psychiatric facility, a patient is often administered medications to reduce agitation and given sedatives instead of receiving comprehensive treatment.

There are fewer than 40,000 total psychiatric beds in the United States, which is why so many in acute psychiatric episodes are "boarded" in hospital emergency rooms.
In a worst-case scenario, the patient is discharged without proper treatment (as was the case of "Gus" Deeds, the deceased son of Virginia State Senator Creigh Deeds).

If a bed becomes available, the ER patient may be admitted. But low-income and disabled persons do not have that option. Medicaid will not pay for emergency psychiatric inpatient treatment if the hospital has more than 16 beds. This arbitrary limit is restructured under the Helping Families in Mental Health Crisis Act to allow for more humane treatment and true stabilization (on average less than 30 days), rather than the cycle of police transport, "boarding," discharge, police transport, jail cell, and discharge.

The idea that eliminating the psychiatric bed shortage will result in unnecessary hospitalizations is as absurd as saying there will be more cases of cancer if the number of cancer treatment centers is increased. There are almost ten million cases of serious mental illness each year; 3.6 million persons do not have the advantage of receiving treatment. SMI is a real illness caused by neurological factors and it can be treated with a spectrum of medical approaches including medication, proper psychotherapy, community services and peer support. But not all cases are equal. When a person with SMI is in an acute crisis stage they often need, and benefit from, a short-term hospitalization for the purposes of stabilization. At these times of crisis, police are typically called in as the individual becomes unnecessarily entangled in the criminal justice system rather than placed in medical treatment.

When working to stabilize a patient with mental illness, it can sometimes take several weeks before a new medication takes full effect. To allow for stabilization and provide the time necessary for medications to do what they were designed to do, it is a medical necessity to provide crisis inpatient care for those who cannot function in the community. The necessity of this medical model stems from the neurological condition, anosognosia, which impairs executive function through a disruption of the pathways in the brain's frontal lobe. Anosognosia limits the ability of half of individuals experiencing schizophrenia and forty percent of individuals experiencing bipolar disorder to recognize they have an illness. For individuals experiencing schizophrenia, the manifestation of the neurological symptom anosognosia is the most actuating predictor of difficulty in long-term adherence to a treatment model.

The Helping Families in Mental Health Crisis Act creates two narrow exceptions to the IMD exclusion:

1. It establishes an optional benefit under Medicaid to permit federal Medicaid matching payments for short-term, acute, psychiatric hospital services as defined in Section 1861(f) of the Social Security Act if these hospitals have a facility-wide average length of stay of less than 30 days on an annual basis for individuals between the ages of 21-64. In addition to psychiatric hospitals, acute care units within state-operated psychiatric hospitals would also be permitted to receive federal matching Medicaid payments for patients between the ages of 21-64.

2. It establishes an optional benefit under Medicaid to permit federal Medicaid matching payments for community residential treatment for persons between the ages of 21-64, commonly called Psychiatric Residential Treatment Facilities

(PRTF), as authorized in Section 1905(a)(16) and (h) and further defined in 42 Code of Federal Regulations 440.160 and 441 Subpart D.

The legislation does not rebuild asylums or state mental hospitals, nor does it promote institutionalization over community-based care. From establishing high quality community behavioral health clinics to integrating behavioral and mental healthcare[2], H.R. 3717 strengthens the community system of care so persons with mental illness receive treatment in the least restrictive setting. In fact, the legislation provides innovative alternatives to involuntary inpatient hospitalization and imprisonment.

Alternatives to Institutionalization

A cornerstone principle of the Helping Families in Mental Health Crisis Act (HFMHCA) is promoting community-based living and the supportive services necessary for persons with mental illness. Let's be clear: just because we do not institutionalize those with mental healthcare needs in a psychiatric hospital does not mean this population avoids institutionalization. We have switched out a hospital bed for a jail cell. My legislation invests in community-based care, not institutionalized care. For instance, Title II of the HFMHCA specifically requires new federally-qualified behavioral health clinics to adopt peer support and recovery model services. Created by Title I of H.R. 3717, the National Policy Laboratory tests emerging best practices to develop evidence-informed treatments that can be adopted by community mental health centers. The Policy Lab would be responsible for testing and comparing new ideas; promoting effective treatments like the Recovery After Initial Schizophrenia Episode (RAISE); disseminating emerging practices like peer support and the recovery model; and collecting and analyzing outcomes data using public health measures like suicide rates, incarceration, and hospitalization.

There are ways of building a cooperative and inclusive approach to care and these should always come first. This includes honest and open communication between providers, consumers and, where appropriate, family and guardians. To assist in this process, a person with mental illness may create an "advanced directive," which is a legal document describing how care should be delivered during a mental health crisis and who is authorized to be involved in communications and decision making. However, such orders do not work in all cases. Most persons with SMI wait an average of 112 weeks before receiving treatment, and in many cases, not until they are in a true crisis situation. Furthermore, with anosognosia afflicting half of persons with SMI, many individuals will never write an advanced directive and will refuse treatment because they lack awareness of their symptoms and the seriousness of their condition.

Assisted Outpatient Treatment (AOT) is proven to be an effective alternative to involuntary inpatient hospitalization. AOT reduces incarceration, homelessness, and emergency room visits by upwards of 70 percent. The Helping Families in Mental Health

[2] H.R. 3717 achieves integrated care in several ways. For instance, the legislation requires federally-qualified behavioral health clinics created by Title II to provide basic primary care services. Second, Title IX extends incentives for adoption of electronic medical records systems under the HITECH Act to include providers of behavioral healthcare services such as psychologists and free-standing psychiatric hospitals.

Crisis Act does require the **four** remaining states that do not have AOT laws, as a condition of receiving a federal mental health block grant, to pass a law authorizing, but not requiring, counties or local jurisdictions to use AOT.

The Helping Families in Mental Health Crisis Act establishes a grant program for counties to properly stand up and administer AOT programs. This grant program was included in the Protecting Access to Medicare Act (Public Law 113-93, 4/2/14).

The HFMHCA also encourages states to adopt a "gravely disabled" standard instead of the "imminent danger" standard to determine when a person needs immediate medical treatment for a mental illness. Currently, twenty-seven states require a person to be threatening harm to himself, herself, or someone else before treatment will be administered. This standard is a cruel anachronism of 18th century so-called "lunacy" laws[3]. Since then, our understanding of mental illness and the science behind it have advanced appreciably. We are unable to predict accurately when a violent psychotic break will occur in a person with mental illness, but we do know that if treatment is not given, the individual's condition will deteriorate into an irreversible state of despair. They will not be unable to manage their own affairs and they will be at a significantly greater risk of jail, homelessness, and suicide. Early treatment is vital for helping them lead fulfilling and productive lives in the community.

The AOT model advanced in H.R. 3717 is only for those most difficult-to-treat patients who have been failed by the voluntary system of care and meet the following definition:

- "has a history of violence, incarceration, or medically unnecessary hospitalizations;"
- "without supervision and treatment, may be a danger to self or others in the community;"
- "is substantially unlikely to voluntarily participate in treatment;"
- "may be unable, for reasons other than indigence, to provide for any of his or her basic needs, such as food, clothing, shelter, health, or safety;"
- "has a history of mental illness or condition that is likely to substantially deteriorate if the patient is not provided with timely treatment; or"
- "due to mental illness, lacks capacity to fully understand or lacks judgment to make informed decisions regarding his or her need for treatment, care, or supervision."

AOT is not coercion; it is an option for persons who have been, and will likely be again, involuntarily committed to a hospital as a result of their illness. These are individuals who have been repeatedly failed by the current system of care and are notoriously difficult to treat. AOT gives a person the power to function in the community with the highest degree of independence, including their own housing and employment as

[3] Deutsch, Albert. "The Mentally Ill in America. A History of Their Care and Treatment From Colonial Times." 1946. Columbia University Press.

possible. It is far more limiting to sentence this person to jail, homelessness, "boarding" in an ER gurney, or suicide. Neither AOT nor any form of involuntary treatment should be used on a person who does not need it.

AOT's effectiveness has been proven in multiple studies. In 2005, the New York State Office of Mental Health conducted a major review of the state's own AOT statute, known as "Kendra's Law." The state experienced the following results with patients who participated in AOT:[4]

- 90% said AOT made them more likely to keep appointments and take medication
- 88% said they and their case manager agreed on what is important for them to work on
- 87% of said they were confident in their case manager's ability to help them
- 87% fewer experienced incarceration
- 83% fewer experienced arrest
- 81% said AOT helped them get and stay well
- 77% fewer experienced psychiatric hospitalization
- 75% reported that AOT helped them gain control over their lives
- 74% fewer participants experienced homelessness
- 55% fewer recipients engaged in suicide attempts or physical harm to self
- 49% fewer abused alcohol
- 48% fewer abused drugs
- 47% fewer physically harmed others
- 46% fewer damaged or destroyed property
- 43% fewer threatened physical harm to others

Overall:

- The average decrease in harmful behaviors was 44%
- The length of hospitalization was reduced 56% from pre-AOT levels
- Adherence to medication increased by 51%.

Those with serious and persistent mental illness currently use an enormous amount of resources. In Maryland alone, just 500 people with SMI cost the state $36.9 million in medical expenses.[5] AOT not only produces better outcomes, but it enables states to reduce medical costs associated with treating individuals with SMI, thereby freeing up money that can instead be used for wraparound services for individuals.

It is also important to note that those experiencing mental illness are victimized at a rate four times higher than the general public, including higher rates of rape, robbery, and assault. According to a study published in the *American Journal of Psychiatry*, individuals with serious mental illness who were not in AOT "were almost twice as likely

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[4] March 2005 N.Y. State Office of Mental Health "Kendra's Law: Final Report on the Status of Assisted Outpatient Treatment." http://www.omh.ny.gov/omhweb/kendra_web/finalreport/

[5] Boronow, John J. and Stephen S. Sharfstein, MD. "Close the mental health revolving door." *Baltimore Sun.* 29 Dec. 2013.

to be victimized as were outpatient commitment subjects."[6] The authors concluded that "outpatient commitment reduces criminal victimization through improving treatment adherence, decreasing substance abuse, and diminishing violent incidents"[7] that may evoke retaliation.

A person with SMI has a right to get care and get better so they can function at their best. It is the values of others imposed upon them that they have a "right" to live a life of victimization, hopelessness, and incarceration, or worse, to die with their rights on.

Reauthorization of the Substances Abuse and Mental Health Services Administration

The Helping Families in Mental Health Crisis Act reauthorizes more than a dozen mental health programs within SAMHSA while restoring Congress' proper oversight role of agency activities and grant-making. The legislation places new emphasis on the hardest-to-reach patients while phasing out programs and grants that are ineffective, unproven, and have not been authorized. No federal agency should be permitted to spend tax dollars on unauthorized activities let alone an agency directed to care for some of the country's most vulnerable citizens.

SAMHSA was created in 1992 with the hope of improving mental health care and reducing substance abuse. Since SAMHSA's founding, there has been an increase in homelessness, incarceration, and suicide amongst those with SMI. By any objective standard, the agency's record would be judged a failure.

In 1992, 7.2 percent of the jail population had a serious mental illness.[8] Today, an estimated 14.5 percent of male inmates and 31 percent of female inmates have an SMI.[9] At some prisons, nearly half of all inmates have a mental health disorder.

In the early 1990s, 5.8 percent of the population aged 12 or older abused illicit drugs.[10] Today, an estimated 9.2 percent of the population has a drug abuse problem according to SAMHSA .[11]

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[6] Hiday, Virginia A., Swartz, Marvin S., Swanson, Jeffrey W., Borum, Randy, and H. Ryan Wagner. 2002. "Impact of Outpatient Commitment on Victimization of People with Severe Mental Illness." *American Journal of Psychiatry* 159: 1403-1411.

[7] Ibid.

[8] Torrey EF, Stieber J, Ezekiel J, Wolfe SM, et al. Criminalizing the Seriously Mentally Ill: The Abuse of Jails as Mental Hospitals. Washington, D.C.: National Alliance for the Mentally Ill and Public Citizen's Health Research Group; 1992.

[9] Psychiatric Services Journal study Prevalence of Serious Mental Illness Among Jail Inmates by Henry J. Steadman, Ph.D., Fred C. Osher, M.D., Pamela Clark Robbins, B.A., Brian Case, B.A., Steven Samuels, Ph.D.

[10] SAMHSA, National Household Survey on Drug Abuse: Preliminary Results. http://www.samhsa.gov/data/nhsda/pe1996/rtst1008.htm

[11] http://www.samhsa.gov/data/NSDUH/2012SummNatFindDetTables/NationalFindings/NSDUHresults2012.htm

According to research published in the *American Journal of Public Health*, rates of substance abuse and mental illness amongst the homeless have increased.[12] People with untreated psychiatric illnesses now constitute one-third, or approximately 250,000, of the estimated 744,000 persons who are homeless.

The Helping Families in Mental Health Crisis Act seeks to improve the agency by requiring evidence-informed programs and grants aimed at funding and care for those experiencing serious mental illness. But, to this day, there is not a single mention of the words "schizophrenia" or "bipolar disorder" in SAMHSA's three-year strategic plan.[13] SAMHSA does fund some excellent programs, such as the National Child Traumatic Stress Network and minority fellowship program. It also helps to fund innovative approaches to care, but there must be accountability for any federal program and that means requiring evidence that programs are working. We have standards for every other area of federal funding. Dollars from the Highway Trust Fund will not go toward building a new bridge without extensive reviews of the design, construction, and environmental implications. Congressional committees must review and sign off on construction of new commissaries and recreation centers by the Pentagon when non-appropriated funds are used. People with SMI deserve at least the same kind of accountability for dollars spent. If programs work, they should be expanded. If they do not, the money should be transferred to new or existing ones. If they are unnecessary or redundant, the programs should be combined so more dollars can go towards care of people with mental illness and not for officials and offices in Washington, DC.

The Assistant Secretary for Mental Health and Substance Use Disorders would elevate the importance of mental health to the same plane as physical health. Reports on federal mental health policy dating back to the Carter Administration have consistently identified two major barriers to improving mental health care: fragmented federal policies, and lack of integration between primary and behavioral health. The Helping Families in Mental Health Crisis Act solves both of these problems with the creation of an Assistant Secretary of Mental Health and Substance Use Disorders. This policy solution of establishing an office to coordinate and direct funding is based on an idea developed in part by President Obama's former Assistant Secretary for Planning and Evaluation (ASPE) Sherry Glied and the current ASPE nominee Richard Frank.

Specifically they wrote: "We propose the creation of a new federal agency or authority…with budgetary oversight of all programs that serve people with mental illness." (*Better But Not Well* by Sherry Glied and Richard Frank: 2006).

Additionally, the Government Accountability Office (GAO) has called the lack of coordination among programs to help persons with mental illness a growing issue. GAO found, for example, that across eight federal agencies the federal government spends $2.8

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[12] "Are Rates of Psychiatric Disorders in the Homeless Population Changing?" Carol S. North, MD. *American Journal of Public Health*. January 2004, Vol 94, No. 1.
[13] "Leading Change: A Plan for SAMHSA's Roles and Actions."
http://store.samhsa.gov/shin/content/SMA11-4629/01-FullDocument.pdf

billion on 26 separate homelessness programs. The report states that a fragmented system has led to programs offering similar services for similar populations, as well as inefficiencies in program administration and service delivery across the federal government.

The Assistant Secretary would have the clout of title, experience, profile, and authority to root out waste in programs that are ineffective, inefficient, or redundant. Had an Assistant Secretary been in place in 2008, it would not have taken five years to produce mental health parity regulations. An Assistant Secretary, as created by H.R. 3717, would produce for Congress within one year a report on all federal spending regarding mental health.

Improving Critical Information Sharing With Families and Caregivers

The Helping Families in Mental Health Crisis Act clarifies existing sections of the HIPAA Privacy Rule and codifies those sections in statute so doctors and family members can communicate while a patient is in a mental health crisis. For example, the legislation allows a parent to receive information about their adult child when a provider determines it is in the best interest of the patient. That's no different than current guidance, but frequent misunderstandings and misinterpretations demand a statutory fix.

Under section 164.510(b) of the HIPAA Privacy Rule, a covered entity "may. . . disclose to a family member, other relative, or a close personal friend of the individual, or any other person identified by the individual, the protected health information directly relevant to such person's involvement with the individual's care or payment related to the individual's health care" – as well as the individual's location, general condition, or death – except in situations where the patient has expressly objected. While this language is in the privacy rule now, it is clear from multiple hearings, dozens of families who have contacted me directly, and the 70,000 complaints about HIPAA made to the Health and Human Services Office of Civil Rights, that statutory clarification is necessary in order to ensure the best possible outcomes for persons with mental illness.

This legislation singles out no one. It makes no mention of autism or any developmental condition. It is strictly designed to address problems that arise when a person with a serious mental illness lacks insight into their condition.

If a person had a stroke, or was unconscious after an automobile accident, doctors would not hesitate to treat the patient, talk to family members to obtain a full medical history, and discuss the treatment plan. An accurate history is just as essential for the care of someone with SMI. Treating without that history is akin to telling an orthopedic surgeon you cannot look at an X-ray, or telling a brain surgeon you cannot see the MRI. Doctors must know what medications a person is on, and what behaviors they have been exhibiting. Without that information, an accurate diagnosis is extremely difficult to make in an emergency situation and could lead to fatal errors, misdiagnosing a behavior that could be a neurological, endocrine or other condition.

The Protection and Advocacy Program

The Helping Families in Mental Health Crisis Act restores the original intent of the Protection and Advocacy for Individuals with Mental Illness (PAIMI): to stop abuse and neglect of persons with mental illness and promote their right to access medical treatment and get better.

Having PAIMI grantees focus on individual cases of abuse and neglect and protecting the individual rights of persons with mental illness to receive treatment in no way "threatens the hope and well-being of people and families struggling to regain their lives."

In May 2013, the Energy and Commerce Subcommittee in Oversight and Investigations held a hearing on oversight of SAMHSA. The Committee heard from a father, Joe Bruce, about his family's interaction with the Disability Rights Center of Maine (a PAIMI grantee).

Joe's son, William, suffers from severe mental illness, paranoia, and episodes of violence. After a physical altercation with his father in January 2006, Will was committed for involuntary hospitalization. His psychiatrist told the patient and his advocates that William was not likely to improve without medication. Nevertheless, William continued to refuse to take antipsychotics under the counsel of a disability rights attorney. The DRC of Maine counsel coached William on how to refuse medication and answer questions so he would be released from the psychiatric hospital against the recommendation of his physicians and his parents.

The attorney guided William on securing his release, even though his parents worried he was still dangerous, and the psychiatrist had stated that the son was "very dangerous indeed for release to the community."

The attorneys were successful, and once released, William returned home and bludgeoned his mother to death with a hatchet. SAMHSA has made no changes to PAIMI after this incident nor provided documentation and information requested by the Subcommittee about PAIMI grantees' statutory authority to supplant the medical judgment of physicians or parents with their own views.

The PAIMI program is another example of mission creep at SAMHSA. Never authorized to do so, PAIMI grantees have taken it upon themselves to work against families by interfering when well-meaning family members try to ensure a mentally ill loved one receives treatment. PAIMI grantees have filed politically-motivated lawsuits and lobbied against legislation that would help persons with severe and persistent schizophrenia receive care in the community (also known as assisted outpatient treatment). These lobbying activities, which violate federal law[14], currently make up the bulk of PAIMI's operations according to a SAMHSA program report. Under H.R. 3717, these activities would be discontinued and funds re-directed toward treatment for persons with serious

[14] Peters, Amanda J. "Lawyers Who Break the Law: What Congress Can Do to Prevent Mental Health Patient Advocates from Violating Federal Legislation." *Oregon Law Review*, Vol. 89 No. 133, 2010.

mental illness and other successful programs like the National Child Traumatic Stress Network Program.

PAIMI grantees should adhere to the same restrictions on lobbying that other federally-funded legal groups like the Legal Services Corporation must follow. Patient and Advocacy organizations like the Disability Rights Network (DRN) receive more than 95 percent of their funds from the federal government through eight separate programs. H.R. 3717 only restructures one of those eight programs. The majority of the federal funds that the DRN receives from the federal government come from the other seven other programs:

- PADD (Protection and Advocacy for Individuals with Developmental Disabilities)
  - Developmental Disabilities Assistance and Bill of Rights Act of 1975
- CAP (Client Assistance Program)
  - 1984 Amendments to the Rehabilitation Act
- PAIR (Protection and Advocacy for Individual Rights)
  - 1993 Amendments to the Rehabilitation Act
- PAAT (Protection & Advocacy for Assistive Technology)
  - Technology-Related Assistance for Individuals with Disabilities Act of 1999
- PABSS (Protection & Advocacy for Beneficiaries of Social Security)
  - Ticket to Work and Work Incentive Improvement Act of 1999
- PATBI (Protection & Advocacy for Individuals with Traumatic Brain Injury)
  - Traumatic Brain Injury Act of 1996
- PAVA (Protection & Advocacy for Voting Accessibility)
  - Help America Vote Act of 2002

I thank you for your attention to this matter and am willing to discuss in further detail any of these provisions in H.R. 3717. The fear-mongering and misinformation about H.R. 3717 is disheartening because it only serves to protect those who profit from the nation's broken mental health system. And by denying reform that would deliver care to those with serious mental illness, opponents are further stigmatizing the condition. Individuals with serious mental illness can and do get better, but their hope for recovery is dashed when anti-psychiatry activists deny access to treatments that can help.

Too many families in crisis are suffering as a loved one's illness goes untreated. For years, they have had nowhere to turn because the programs and resources have never fully focused on their needs. Without lobbyists or taxpayer funding, these families have been up against a system that shuts them out, denies their loved one acute psychiatric care, and cruelly requires a person to be violent or commit a crime before they can access treatment. This status quo is no longer tolerable. I will not stop until we have reformed this broken system and remain fully engaged with anyone willing to work on good ideas for helping these neglected and vulnerable families in crisis. I look forward to working with you to see the Helping Families in Mental Health Crisis Act signed into law.

Sincerely,

Tim Murphy
Member of Congress

Cc: The Honorable Marsha Blackburn, Vice Chairman, Energy and Commerce Committee
The Honorable Joe Pitts, Chairman, Subcommittee on Health
The Honorable Frank Pallone, Ranking Member, Subcommittee on Health
The Honorable Diana DeGette, Ranking Member, Subcommittee on Oversight & Investigations
The Honorable John Boehner, Speaker, House of Representatives
The Honorable Eric Cantor, Majority Leader, House of Representatives
The Honorable Kevin McCarthy, Majority Whip, House of Representatives
The Honorable Cathy McMorris Rodgers, Chairwoman, House Republican Conference
The Honorable James Lankford, Chairman, House Republican Policy Committee
Vice President Joseph R. Biden
The Honorable Nancy Pelosi, Minority Leader, House of Representatives