HELPING FAMILIES IN MENTAL HEALTH CRISIS ACT OF 2013

HEARING

BEFORE THE

SUBCOMMITTEE ON HEALTH

OF THE

COMMITTEE ON ENERGY AND COMMERCE
HOUSE OF REPRESENTATIVES

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[1] Dr. Welner's response to submitted questions for the record can be found at *http://docs.house.gov/meetings/if/if14/20140403/102059/hhrg-113-if14-wstate-welnerm-20140403-sd002.pdf*.

[2] The statement can be found at *http://docs.house.gov/meetings/if/if14/20140403/102059/hhrg-113-if14-20140403-sd008.pdf*.

HELPING FAMILIES IN MENTAL HEALTH CRISIS ACT OF 2013

THURSDAY, APRIL 3, 2014

House of Representatives,
Subcommittee on Health,
Committee on Energy and Commerce,
Washington, DC.

The subcommittee met, pursuant to call, at 10:31 a.m., in room 2322 of the Rayburn House Office Building, Hon. Joe Pitts (chairman of the subcommittee) presiding.

Present: Representatives Pitts, Burgess, Murphy, Blackburn, Gingrey, Lance, Cassidy, Guthrie, Griffith, Bilirakis, Ellmers, Upton (ex officio), Pallone, Capps, Schakowsky, Green, Butterfield, Barrow, Christensen, Sarbanes, DeGette, Tonko, and Waxman (ex officio).

Staff present: Clay Alspach, Chief Counsel, Health; Mike Bloomquist, General Counsel; Sean Bonyun, Communications Director; Karen Christian, Chief Counsel, Oversight; Noelle Clemente, Press Secretary; Brenda Destro, Professional Staff Member, Health; Brad Grantz, Policy Coordinator, Oversight and Investigations; Sydne Harwick, Legislative Clerk; Robert Horne, Professional Staff Member, Health; Katie Novaria, Professional Staff Member, Health; Sam Spector, Counsel, Oversight; Heidi Stirrup, Health Policy Coordinator; Tom Wilbur, Digital Media Advisor; Ziky Ababiya, Democratic Staff Assistant; Karen Lightfoot, Democratic Communications Director and Senior Policy Advisor; Karen Nelson, Democratic Deputy Committee Staff Director for Health, Anne Morris Reid, Democratic Senior Professional Staff Member; and Matt Siegler, Democratic Counsel.

OPENING STATEMENT OF HON. JOSEPH R. PITTS, A REPRESENTATIVE IN CONGRESS FROM THE COMMONWEALTH OF PENNSYLVANIA

Mr. Pitts. The subcommittee will come to order. The Chair will recognize himself for an opening statement.

Millions of Americans suffer with severe mental illnesses, such as bipolar disorder, schizophrenia, and major depression, and many of them, and their families, struggle to find the treatment and help they desperately need.

I would like to commend my colleague from Pennsylvania, Dr. Murphy, for his yearlong investigation into mental health issues and for proposing H.R. 3717, the Helping Families in Mental Health Crisis Act. Briefly, this bill would reform the Community Mental Health Services Block Grant program by changing administration, improving data collection, and by requiring treatment standards to facilitate care. It would enhance Medicaid payments to Federally Qualified Community Behavioral Health Centers (FQCBHCs), make adjustments to HIPAA and FERPA—the Family Education Rights and Privacy Act—privacy regulations, and expand access to certain medical records for qualifying caregivers; create an Assistant Secretary for Mental Health who will be responsible for coordinating spending at all federal agencies on mental health, including at the Substance Abuse and Mental Health Services Administration (SAMHSA). It would make changes to key Justice Department regulations that impact at-risk or imprisoned individuals with mental illness. It would increase federal funding for certain Medicaid providers and research at the National Institutes of Health. It would institute liability protections for physician volunteers at FQCBHCs, and it would reform existing mental health programs at SAMHSA.

I would like to welcome all of our witnesses here today. We look forward to learning from your expertise and experience.

[The prepared statement of Mr. Pitts follows:]

PREPARED STATEMENT OF HON. JOSEPH R. PITTS

The Subcommittee will come to order.

The Chair will recognize himself for an opening statement.

Millions of Americans suffer with severe mental illnesses, such as bipolar disorder, schizophrenia, and major depression, and many of them—and their families—struggle to find the treatment and help they desperately need.

I would like to commend my colleague from Pennsylvania, Dr. Murphy, for his year-long investigation into mental health issues and for proposing H.R. 3717, the Helping Families in Mental Health Crisis Act. Briefly, this bill would:

- Reform the Community Mental Health Services Block Grant Program by changing administration, improving data collection, and by requiring treatment standards to facilitate care;
- Enhance Medicaid payments to Federally Qualified Community Behavioral Health Centers (FQCBHCS);
- Make adjustments to HIPAA and FERPA (the Family Education Rights and Privacy Act) privacy regulations and expand access to certain medical records for qualifying caregivers;
- Create an Assistant Secretary for Mental Health who will be responsible for coordinating spending at all federal agencies on mental health, including at the Substance Abuse and Mental Health Services Administration (SAMHSA);
- Make changes to key Justice Department regulations that impact at-risk or imprisoned individuals with mental illness;
- Increase federal funding for certain Medicaid providers and research at the National Institutes of Health;
- Institute liability protections for physician volunteers at FQCBHCS; and
- Reform existing mental health programs at SAMHSA.

I would like to welcome all of our witnesses here today. We look forward to learning from your expertise and experience.

Thank you, and I yield the remainder of my time to ______________________.

Mr. PITTS. I will yield the balance of my time to the gentleman from Pennsylvania, Dr. Murphy.

OPENING STATEMENT OF HON. TIM MURPHY, A REPRESENTATIVE IN CONGRESS FROM THE COMMONWEALTH OF PENNSYLVANIA

Mr. MURPHY. I thank the chairman for convening this hearing, and I want to thank the witnesses for being here as well.

In light of yesterday's tragic shooting at Fort Hood involving a soldier under treatment for a behavioral health disorder, and news this week out of Pittsburgh of a mother who said she heard voices commanding her to drown her two young children in a bathtub, today's hearing has a sad element of timeliness to it. But let us keep in mind, most persons with mental illness are not violent, and tragically, are more frequently the victims of violence, but you will never hear the breaking news of a homeless man being robbed or beaten or a person with mental illness losing their job.

Over the last year, the Oversight and Investigations Subcommittee I chair held a series of forums and hearings to review our Nation's mental health system, and this bill, the Helping Families in Mental Health Crisis Act, is a result of those hearings, and with anything, there is misinformation about this legislation, which is why I am glad you have convened this hearing so we can continue to work forward on perfecting it.

Fifty years ago, our Nation confronted the atrocities of asylums, warehouses for those whose illnesses medical science could not yet treat, and at that time this committee moved legislation to close those places and help individuals live in the community. Many were getting treatment and many were not, and for half a century operated under the illusion that having done something, we did the right thing. We didn't.

Unfortunately, that illusion has been shattered by the heartbreaking daily tragedies that prove our mental health system is broken and failing the very people who need help most. The stories are haunting and the numbers are staggering. 3.6 million people with serious mental illness don't get treatment. There are over 40,000 suicides a year, 20 soldier suicides each day. Another 1.3 million attempted suicides.

There is only one child psychiatrist for every 2,000 children with a mental health disorder. It is a system where the three largest mental health hospitals are actually jails, and there is a shortage of 100,000 psychiatric beds nationwide for those who are in acute crisis.

A rule to protect privacy needs clarification because it has frustrated a countless number of physicians and members and generated over 70,000 complaints, and the mental health agency that until recently employed as many dentists as it did psychologists and psychiatrists, and this is what the American taxpayer buys for $125 billion.

That is why we introduced this bill, to engage in meaningful reform. It has several of those elements that just presented by the chairman in empowering parents and caregivers by breaking down the barriers that prevent communication, increases access to acute care psychiatric beds, provides alternatives to inpatient care through assisted outpatient treatment, and expands access to the underserved and rural populations; creates an Assistant Secretary of Mental Health to scrutinize federal programs and promote evidence-based care; ensures mental health patients enrolled in Medicare and Medicaid have access to the full range of medications that keep them healthy and out of the hospital; advances critical research at the National Institutes of Mental Health like the Brain Research Initiative; promotes promising evidence-based care like the recovery after initial schizophrenic episode; improves quality and expands access to integrated medical and mental health care at community mental health providers, extends health information technologies so mental health providers can communicate and work with primary care physicians, and ensures greater accountability from the Substance Abuse and Mental Health Service Administration.

For far too long, those who need help have been getting it the least, and where there is no help, there is no hope. We can, must and will take mental illness out of the shadows of ignorance, despair, neglect and denial and into that bright light of hope, and it starts with the Helping Families in Mental Health Crisis Act.

I look forward to hearing the comments of our witnesses today. I yield back.

Mr. PITTS. The chair thanks the gentleman and now recognizes the ranking member of the subcommittee, Mr. Pallone, for 5 minutes for an opening statement.

OPENING STATEMENT OF HON. FRANK PALLONE, JR., A REPRESENTATIVE IN CONGRESS FROM THE STATE OF NEW JERSEY

Mr. PALLONE. Thank you, Chairman Pitts.

This is our subcommittee's first proceeding on mental health during this Congress, and while I am thankful to you for finally convening a panel to talk about this critically important issue, I remain conflicted and disappointed that you have decided to move straight to a legislative hearing.

For over a year we have had personal and staff discussions about the importance of the Health Subcommittee examining mental health in light of some heartbreaking events in the past couple of years, and despite this today, I and other members of the subcommittee are at a significant disadvantage because we haven't been afforded an opportunity to be at the forefront of evaluating and focusing on mental illness. As the Health Subcommittee, we should be the ones putting a full-scale effort into reviewing this and understanding it better.

Mental illness is an important public health issue. According to numbers from the National Alliance on Mental Health, it is estimated that one in four adults experience a mental illness during the course of a given year. That is about 55.7 million people. Meanwhile, only about 60 percent of people with mental illness get treatment each year. Of these people, approximately 11.4 million adults in the United States live with a serious mental illness, which includes, among others, major depression, schizophrenia, and bipolar disorder. Individuals with serious mental illness can be treated effectively, but unfortunately, it has been so difficult for those who need services to break through the stigma and weigh the obstacles associated with mental health, even though we know how important mental health is and how interlinked it is to all aspects of health and quality of life.

What some people may not realize is that mental illness is not an isolated public health problem. Cardiovascular disease, diabetes, and obesity often coexist with mental illness and treatment of the mental illness can reduce the effects of these disorders. So it is proven that people, families, and communities will benefit from increased access to mental health services. Despite recent vigorous debate about America's mental health policies, there has been no clear solution yet. However, we made some significant steps over recent years. The first significant milestone was the Paul Wellstone Mental Health Parity and Addiction Equity Act, which makes sure that large employer-based insurers cannot charge more or place greater restrictions on mental health benefits that they do for medical benefits. This parity law marked a dramatic and historic step for the rights of Americans with mental health and addiction illness. When I was the chairman of the Health Subcommittee, I was proud to help play a critical role in enacting this bipartisan legislation.

Of course, the parity struggle is not over. The implementation of this law is critical. Specifically, we need to ensure that there are measures in place for meaningful reporting on compliance with the law.

Another significant milestone was passage of the Affordable Care Act. It includes a number of provisions aimed at improving coverage for and access to mental health services. So let me point out some of the critical details in the ACA. First, people can no longer be denied coverage because of preexisting conditions, and this includes mental health illness; more access to the Medicaid program, which has always provided a number of mental health treatments. Mental health treatment now comes standard. Every health plan sold through an exchange has to cover a variety of medical services, which includes mental health and substance abuse treatments. And finally, the ACA extends mental health parity to all Americans, not just those who are covered by large employers, again, building upon the Paul Wellstone law.

Mr. Chairman, these are just the highlights of the law the Republicans aim to repeal. The ACA also includes a number of provisions that specifically list mental health and substance abuse as priority topics in programs like the National Prevention Council, health workforce development initiatives and medical homes, and there is still a lot more to do. People will only benefit from the progress we have made if services are available and if those who need help are not afraid to seek it. We need to build from these laws to support the continuum of mental health services at all levels of government.

That is why I believe we must support efforts to increase awareness about mental health and reduce the fear, shame, and misperceptions that often prevent people from getting the help they need, and I am committing to spreading the message that it is OK to talk about mental health because treatment is effective and people do recover. We must find out which treatments are the right treatments and how we can best identify Americans who need help, and that is why agencies such as the Substance Abuse and Mental Health Services Administration and NIMH are so important.

So Mr. Chairman, there are a number of Democrats on the committee who have introduced legislation and expressed interesting in working together to improve mental health in this country. I hope that if you choose to move forward on the bill under consideration today that we can find common ground and pass bipartisan legislation. I have some serious concerns about some of the provisions of H.R. 3717 but I remain committed to working with you and my other colleagues on the committee as we make mental health a priority.

Thank you, Mr. Chairman.

Mr. PITTS. The chair thanks the gentleman and now recognizes the chairman of the full committee, the gentleman from Michigan, Mr. Upton, for 5 minutes for an opening statement.

OPENING STATEMENT OF HON. FRED UPTON, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF MICHIGAN

Mr. UPTON. Well, thank you, Mr. Chairman.

Mental illness affects millions of Americans and their families, yet sadly it is a subject often left unmentioned in Congress and in communities across the country, and we are working to change that. Yes, we are. Ensuring treatments and resources are available and effectively used for those suffering with mental illnesses has been a priority of this committee throughout the 113th Congress.

Since January of last year, Oversight and Investigations Subcommittee Chairman Tim Murphy has spearheaded a thorough review of all federal mental health programs. The subcommittee and the committee held a series of public forums, briefings and investigative hearings to discern how federal dollars devoted to research and treatment into mental illness are being prioritized and spent. I want to commend him and those of efforts, and those of the ranking member of the Oversight and Investigations Subcommittee, Diana DeGette, to ensure a bipartisan focus on these vital issues.

To address the gaps discovered in the extensive and wide-ranging examination, Chairman Murphy introduced H.R. 3717 last year, the Helping Families in Mental Health Crisis Act of 2013. The bill addresses issues that are important in diagnosing and treating individuals with serious mental illness. It would reorient federal funding for mental health to improve the delivery of mental health services and help improve the lives of mental health patients and their families.

I am pleased that two important provisions of that bill were included in H.R. 4302 that the President signed earlier this week, which was sponsored, of course, the overall bill by Chairman Pitts. The first provision will help local jurisdictions implement assisted outpatient treatment grant programs, and the second will improve access to community mental health services, bipartisan and bicameral support for both of those provisions.

I would just like to add that to those families who have been impacted by mental illness in some form, Congress is aware of your plight and we can do better.

I yield the balance of my time to the vice chair of the subcommittee, Dr. Burgess.

[The prepared statement of Mr. Upton follows:]

PREPARED STATEMENT OF HON. FRED UPTON

Mental illness affects millions of Americans and their families, yet sadly it is a subject often left unmentioned in Congress and in communities across the country. We are working to change that. Ensuring treatments and resources are available and effectively used for those suffering with mental illnesses has been a priority of this committee throughout the 113th Congress.

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To address the gaps discovered in the extensive and wide-ranging examination, Chairman Murphy introduced H.R. 3717, the Helping Families in Mental Health Crisis Act of 2013. The bill addresses issues important in diagnosing and treating individuals with serious mental illness. It would reorient federal funding for mental health to improve the delivery of mental health services and help improve the lives of mental health patients and their families.

I am pleased that two important provisions of H.R. 3717 were included in H.R. 4302, the Protecting Access to Medicare Act of 2014, which was sponsored by Health Subcommittee Chairman Pitts and recently signed by the president. The first provision will help local jurisdictions implement assisted outpatient treatment grant programs, and the second will improve access to community mental health services.

I would just like to add that to those families who have been impacted by mental illness in some form—Congress is aware of your plight and we can do better.

I'd like to thank the witnesses for taking the time to testify before the Subcommittee this morning. I yield the remainder of my time to ————————————————.

Mr. BURGESS. Well, I thank the chairman for yielding. I really do not have prepared comments this morning but I did feel obligated to respond.

I am the vice chairman of this subcommittee as well as the vice chairman of the Oversight and Investigations Subcommittee, and in total, the committee through its subcommittees, this represents the eighth dedicated hearing to mental health and mental health issues between the Oversight and Investigations Subcommittee and the Subcommittee on Health and the full committee in general. So it is not from lack of attention. Chairman Murphy has made this the centerpiece of his chairmanship of the Oversight and Investigations Subcommittee, which is appropriate but that is not a legislative committee, so today we are in the Health Subcommittee, and Chairman Pitts is encouraging us to have this legislation hearing on Congressman Murphy's efforts.

And then as a Texan, I just have to say across the country, our hearts are heavy because of what we saw down in Fort Hood last evening. When the news stories began to break, I am sure I felt the same as everyone else across the country felt: oh, no, not again. It seems like just a few months ago that we were down for the memorial service for the 13 soldiers who were lost in November of 2009, and now we are facing another series of questions surrounding another incident yesterday.

We know there will be an investigation. We know there will be answers to the questions that are forthcoming, but right now please let us keep in our thoughts the soldiers at Fort Hood, their general officer corps, of course the people in Killeen, Texas, Harker Heights, Coppers Cove, those communities. I will tell you from firsthand experience during the memorial service 4 ½ years ago, those communities came together and embraced the soldiers at Fort Hood and let them know they were not acting alone. Our military has been under great stress for the last decade. Surely this is something they didn't need but we can all stand in their support.

Thank you, Mr. Chairman. I will yield back.

Mr. PITTS. The chair thanks the gentleman and now recognizes the ranking member of the full committee, Mr. Waxman, 5 minutes for an opening statement.

OPENING STATEMENT OF HON. HENRY A. WAXMAN, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF CALIFORNIA

Mr. WAXMAN. Thank you, Mr. Chairman.

One in four adults has a diagnosable form of mental illness in any given year. More than 10 million Americans are living with serious mental illness, conditions like schizophrenia and major depression. But even as the demand for mental health services has increased, there has been an unprecedented decline in state public mental health spending. The Federal Government has stepped in to help fill the gap. The increased coverage provided by the Affordable Care Act and the mental health benefits it requires will make a substantial improvement in the lives of Americans who need these services. Already more than 7 million Americans signed up for insurance coverage through the marketplaces that includes mental health and substance use disorder services at parity with medical and surgical benefits.

The expansion of Medicaid in many states, but not all unfortunately, has also made a huge difference, giving millions more comparable behavioral health coverage. But there is certainly more that can be done.

Today's hearing is focused on one bill, legislation introduced by Congressman Murphy, H.R. 3717, the Helping Families in Mental Health Crisis Act of 2013. There are some provisions in H.R. 3717 that I strongly support. I support reauthorization of programs with strong bipartisan backing like the Garrett Lee Smith Suicide Prevention program and National Child Traumatic Stress Initiative. I support the provisions recognizing the important work of the National Institute of Mental Health on brain research that will help us better understand the causes of mental illness. I support the campaign to raise awareness regarding mental illness among our young people, and I support the proposal that would extend electronic health record meaningful use incentive payments to mental health providers.

But I must express deep concern about other provisions in this bill. I think the bill broadly redefines the privacy rights of individuals with a diagnosed mental illness. This could discourage many people who need to come forward for care from seeking necessary treatment if they fear their privacy won't be protected. The bill cuts federal support for mental health services administered through the Community Mental Health Services Block Grant and conditions States' ongoing support on the adoption of new federal standards for involuntary treatment that would displace current law. So you have the Federal Government cutting the funds but saying if you are going to get funds that are left, you have to do it the way we tell you to do it. This has always been a State responsibility. This is a one-size-fits-all response. I am not sure if that is the best way for us to approach it.

It proposes a dramatic reorganization of mental health authorities in the Department of Health and Human Services that would minimize the role of the main agency on mental health—the Substance Abuse Mental Health Services Administration—and would reverse efforts to better coordinate mental health and substance abuse activities. Separation of these two programs—I can't understand the reasoning behind it. And the bill undermines the important work of the protection and advocacy programs that protect the rights of people with mental illness from abuse and neglect.

The bill has an important provision in it that I think we need to look very carefully at, and that is the expansion of Medicaid coverage that we are going to mandate under Medicaid, and I think the responsibility of the states that have been paying for it and shifting those costs to the Federal Government. This could be billions and billions and billions of dollars at a time when we hear so often from the other side of the aisle we can't afford the entitlements of Medicaid the entitlements of poor people, and a lot of poor people have the greatest problem in accessing mental health services.

Last year, I and other Democrats introduced mental health legislation but key provisions from that legislation are absent in Congressman Murphy's bill. Any bill we advance should include investments in mental health first aid, mental health in the schools, and mental health provider workforce development. We should be looking at all ideas that have been put forward and working in a bipartisan manner on legislation to achieve our shares the goal of improving our system.

I want to thank all of the witnesses for appearing before us today. In particular, I want to take a moment to recognize Ms. Jensen, who will share her own personal history with mental illness and road to recovery. I also want to acknowledge Ms. Thompson, who is a constituent of mine, and will discuss her experience as the daughter of a mother with serious mental illness. And Ms. Zdanowicz, I know family members close to you also have a history of mental illness, and that is true of Dr. Shern as well. It takes a great deal of courage for you to come here and speak out publicly about such difficult experiences, but it is important for the subcommittee to hear your perspectives and to share it with our other colleagues in the Congress.

Thank you, Mr. Chairman.

Mr. PITTS. The Chair thanks the gentleman. That concludes opening statements. All members' opening statements will be made a part of the record.

I have a UC request. At this time I would ask unanimous consent to enter these documents into the record: one by the American Psychiatric Association, a Wall Street Journal article titled "The Definition of Insanity: How a Federal Agency undermines treatment for the Mentally Ill," a statement by Robert Bruce, another Wall Street Journal article dated December 26, 2013, and an oped by Congressman Murphy that appeared in the Philadelphia Inquirer January 26, 2014. Without objection, so ordered.

[The information appears at the conclusion of the hearing.]

Mr. PITTS. We have one panel today with five witnesses. I will introduce them in the order that they speak. Unfortunately, our first witness, Dr. Michael Welner, is still on a train delayed. He will be coming in at any minute. He is Founder and Chairman of the Forensic Panel. Ms. Sylvia Thompson, Patient Advocate and President of the National Alliance on Mental Illness; Dr. David Shern, Interim President and CEO of Mental Health America; Ms. Nancy Jensen, a person with lived experience, and Ms. Mary Zdanowicz, Attorney and former Executive Director of the Treatment Advocacy Center.

Thank you all for coming. Your written testimony will be made a part of the record. You will each be given 5 minutes to summarize your written testimony, and we will begin with Ms. Thompson. Ms. Thompson, you are recognized for 5 minutes.

STATEMENTS OF SYLVIA THOMPSON, PATIENT ADVOCATE AND PRESIDENT, NATIONAL ALLIANCE ON MENTAL ILLNESS, WEST SIDE LOS ANGELES; DR. DAVID L. SHERN, INTERIM PRESIDENT AND CEO, MENTAL HEALTH AMERICA, ALEXANDRIA, VIRGINIA; NANCY JENSEN, PERSON WITH LIVED EXPERIENCE, WICHITA, KANSAS; AND MARY T. ZDANOWICZ, ATTORNEY, NORTH EASTHAM, MASSACHUSETTS

STATEMENT OF SYLVIA THOMPSON

Ms. THOMPSON. Thank you, Mr. Chairman and members of the committee, Representative Waxman. My name is Sylvia Thompson and I am a Professional Care Manager as well as President of NAMI's West Side Los Angeles affiliate, but that is not why I am here today.

Today I am my mother's daughter. My mother was severely mentally ill from as far back as I can remember. So growing up in my family was like living in a combat zone. It never felt safe because of her drastic mood changes, paranoia, grandiose ideas, impulsivity, delusions, depression and inappropriate anger often directed at me. As much as we loved our mother, my family was powerless to help her because she did not believe she was ill. It is called anosognosia. It affects up to 40 percent of those with schizophrenia and bipolar disorder, and that is a conservative estimate. Because she didn't believe she was ill, she would not stay in treatment so she could not take care of herself nor could she take care of me. She had suicidal ideation, delusions, hospitalizations, believed I was possessed, and would disappear for days or weeks.

I am a firm believer in self-determination but for those that are capable. We must recognize there is a whole group of people like my mother who are too ill to self-direct their own care. Just take a look at the news. We can't pretend these people don't exist. These tragic stories like this morning, they are not the face of mental illness. They are the face of mental illness that is severe mental illness that is left untreated.

Our helpline is flooded with calls from family members of individuals who are imprisoned by their delusions and hallucinations. Parents beg for treatment and cannot get it. The current mental health system doesn't help them because their child is too ill to volunteer for treatment. The police can't help until after they become dangerous. It can't be a recovery model or a medical model. We must embrace both because one size does not fit all.

Sometimes the recovery model works but sometimes assisted outpatient treatment or involuntary hospitalization is initially necessary to get somebody on the recovery path. AOT would help the few who have a past history of multiple arrests, violence or hospitalizations caused by refusing to stay in treatment. Studies show AOT reduces homelessness, incarceration, suicide, arrest, and yes, violence. It saves money. It reduces force and it saves lives. We need more hospital beds. California has only five state hospitals with less than 7,000 beds. Because of that, Californians with severe mental illness are four times more likely to be incarcerated than hospitalized—four times. That would never be tolerated for cancer or Alzheimer's disease. Even at its best, California would be short over 10,000 hospital beds to help the most severely mentally ill get stabilized. We can't pretend that hospitals are not needed.

We have to free family caretakers from HIPAA handcuffs so they can provide care to loved ones. How can someone ensure their loved one has transportation to an appointment if they don't know when the appointment is, or ensure they stay on their medications if they don't know what the medicines are. We have to prioritize the most severely ill and stop funding non-evidence-based programs and groups that impede care for the most seriously ill.

Congress created SAMHSA to target mental health services to the people most in need. Only four in the 288 programs in SAMHSA's national registry of evidence-based practices focus on severe mental illness. That is four out of 288.

I urge you to pass H.R. 3717. I am not a politician, I am not a legislator, but I am someone who has spent her life in the trenches personally and now professionally. It is wonderful to want to improve mental health for everyone but in the process we absolutely cannot ignore the most severely ill. They are the most vulnerable and they need your help.

My mother struggled my whole life. Before we gained guardianship, she was living in a state of squalor surrounded by stacks of newspaper, rotten food, human feces, dead rodents. That was how she self-directed her care. No one chooses that life. But you should also know, she spoke seven languages fluently. She knew every opera libretto and she was a gifted pianist. She was passionate, she was creative and she was loving. She was someone's daughter, she was someone's sister, she was someone's wife, and she was the mother to six amazing children who were desperate for her to be well again.

My mother's inability to acknowledge her illness was not a choice. It was a symptom that trapped her and robbed all of us of her greatness, robbed me of my mother. I am proud to be my mother's daughter. I inherited her passion, her creativity, her outside-the-box thinking. In her memory and to prevent others from going through what she and our family did, I implore you all to please work together to pass H.R. 3717. Thank you.

[The prepared statement of Ms. Thompson follows:]

Recommendations of
Sylvia Thompson, BA, CMC
President, NAMI Westside Los Angeles
Daughter of someone with serious mental illness
to
US House of Representatives Committee on Energy and Commerce Subcommittee on Health
In SUPPORT of HR-3717: Helping Families in Mental Health Crisis Act
April 4, 2014

I recommend passing HR 3717 and especially support the following provisions which will help get treatment to the most seriously ill.

1. Implement IMD Reform: The Institutes for Mental Disease Exclusion prevents states from receiving Medicaid reimbursement for the mentally ill who are so ill they need to be hospitalized for an extended period. So states kick the seriously mentally ill out of hospitals to make them Medicaid eligible. Many wind up incarcerated. HR3717 makes small revisions in Medicaid so those who need hospital care can receive it.

2. Require states to have AOT as a condition to receive block grants and fund pilot AOT programs: AOT is exclusively for those who have a history of multiple arrests, violence, incarcerations or hospitalizations due to going off treatment. It allows judges to order them into mandated and monitored treatment and order the mental health system to provide the care. AOT reduces homelessness, arrest, hospitalization and incarceration over 70% each. It saves 50% by providing an off-ramp before more expensive and restrictive inpatient commitment or incarceration become needed. 75% of those in the program say it helps them get well and stay well. DOJ certified it as an effective crime prevention program.

3. HIPAA/FERPA Reform: This alone would help the lives of so many people I try to help. HIPAA and FERPA require doctors to keep families in the dark absent a specific waiver by the mentally ill individual. Neither James Holmes nor Jared Loughner gave the waiver, hence their parents did not know school authorities identified them as needing help. Families need the information about their mentally ill loved ones so they can ensure they have prescriptions filled, transportation to appointments, and stay in treatment. HR 3717 writes limited exclusions into HIPAA law so family/caregivers get the same information paid caretakers would receive.

4. Eliminate anti-treatment activities at SAMHSA/CMHS: Congress created SAMHSA to "target ... mental health services to the people most in need". SAMHSA fails to focus on the seriously ill and funds programs and groups that make care more difficult. Only four of the 288 programs in the SAMHSA National Registry of Evidence Based Practices are for people with serious mental illness. SAMHSA uses block grant funds to coerce states to replace the medical model with SAMHSA's recovery model, which requires people self-direct their own care. The most seriously ill, who are psychotic and delusional, cannot self-direct their own care. SAMHSA suggests everyone recovers, thereby ignoring those so ill they do not.

5. Reform PAIMI: PAIMI was founded with the noble purpose of helping to improve the quality of care received by the most seriously ill. It now focuses on 'freeing' them from treatment. It has evolved into a lobbying machine that discourages states from spending on the most seriously ill. HR 3717 returns Protection and Advocacy for Individuals with Mental Illness to their original mission of helping persons with mental illness access care and reigns in their ability to use funds lobbying against treatments (ex. hospitals) needed by some of the seriously ill.

6. Create Assistant Secretary to focus federal efforts on the most seriously ill: HR 3717 creates an Assistant Secretary for Mental Health to distribute block grants formerly distributed by SAMHSA and help the system address the elephant in the room: getting treatment to people known to have untreated serious mental illness. The Secretary would eliminate non-evidenced based practices, provide better coordination of federal resources, reduce duplication, and require the prioritization of the seriously ill.

Testimony of
Sylvia Thompson, BA, CMC
President, NAMI Westside Los Angeles
Daughter of someone with serious mental illness
to
US House of Representatives Committee on Energy and Commerce
Subcommittee on Health
In SUPPORT of HR-3717: Helping Families in Mental Health Crisis Act
April 4, 2014

Thank you Mr. Chairman, members of the Committee and my own Representative Waxman. My name is Sylvia Thompson and I am a professional client advocate and Care Manager as well as the President of the National Alliance on Mental Illness, Westside Los Angeles affiliate. But that is not why I am here today.

Today I am my mother's daughter. I never knew anything other than a life surrounded by serious mental illness. My mother was seriously mentally ill from as far back as I can remember. Growing up in our family was like living in a combat zone where my mother's serious mental illness terrorized every one of us. It never felt safe because you didn't know when the other boot was going to drop. The drastic mood changes, intense paranoia, grandiose ideas, impulsivity, delusions, depression, and inappropriate anger created a frightening environment for a child who depended on her. This led to emotional and physical neglect, as well as emotional, verbal, and, at times, physical abuse. And yet, I loved my mother. I watched as my father, and later my siblings and I, were powerless to help her.

My mother had zero insight into her illness. She did not believe she was ill. We call that anosognosia[1]. It affects up to 40% of those with schizophrenia and bipolar. Because she didn't believe she was ill, she would not stay in treatment and as a result could not take care of herself, let alone me. She had suicidal ideation, delusions I was possessed, multiple hospitalizations, and would disappear for spells of time...sometimes hours, sometimes weeks and we were powerless to do anything but watch her deteriorate.

I went to college and got a degree in Psychology, became a patient advocate for the most vulnerable population, and now President of NAMI Westside LA. I know what would have helped my mother and what would help the countless faces of serious mental illness I see day after day. Much of that is in HR 3717. It is the first bill to address the needs of the most seriously ill as opposed to the many bills that focus on helping the much higher functioning.

I believe in self-determination for those who are capable but **we must recognize** that there is a small group of people, like my mother, who are too ill to self-direct their own care. To take the extreme case, John Hinckley was self-directing his own care when he decided the best way to get a date with Jodi Foster was to shoot President Reagan. We can't pretend these people don't exist because by doing so, we marginalize them. They are our loved ones. Our helpline gets calls everyday from parents, children, siblings, and spouses of individuals who are so ill they can't acknowledge it and so refuse treatment. They cower in their rooms believing the FBI planted a transmitter in their head. They refuse to eat for fear of being poisoned. They believe their young daughter is the child of the devil and will kill them in a great battle. The mental health system won't help them because they are not well enough to volunteer for treatment. The police can't help until after they become dangerous. Laws should prevent dangerous behavior not require it. How I wish everyone was well enough to take care of themselves and use voluntary services but some are not.

We need Assisted Outpatient Treatment. (AOT)
What would have helped my mother and would help some of those who call our helpline would be to have Assisted Outpatient Treatment as provided for in HR 3717. While some opponents cite old research on this (Appendix: Myths about Laura's Law) I have reviewed the recent research for New York (Appendix: Recent Kendra's Law Studies) and California (Appendix: Laura's Law Results in two counties) and the results are exceedingly clear: AOT reduces homelessness, incarceration, suicide, arrest, and yes, violence. It is for very few of the most seriously ill, only those with a past history of multiple incidents of arrest, violence or hospitalization caused by refusing to stay in treatment. By providing an off-ramp before involuntary commitment and incarceration it saves money and, more importantly, it saves lives.

We need enough hospital beds for the most seriously ill who need hospitalization.
We are in dire need of more hospital beds, something HR 3717 addresses. I deal with calls from families wondering what they have to do to help get a loved one who needs hospital care into a hospital. California has only 5 state hospitals with less than 7,000 beds[2]. 90% of those who get into California psychiatric hospitals do so through the criminal justice system not the mental health system[3]. In California individuals with serious mental illness are four times more likely to be incarcerated as hospitalized.[4] Admission, without becoming a danger to self or others, is virtually impossible. That is criminalizing an illness. Can you imagine that for Cancer or Alzheimer's Disease? Even if California had a perfect community based mental health system, we are still short over 10,000 hospital beds to help the seriously ill get stabilized well enough for release. Again, we can't pretend that hospitals are not needed by anyone. Some with a serious mental illness **do need** hospitalization to get stabilized.

We have to free family caretakers from HIPAA Handcuffs so they can provide care to loved ones.
HIPAA and FERPA prevent families from getting information they need to provide care to seriously mentally ill loved ones. The information is readily available to programs that are paid to provide case management services or paid to provide housing for the mentally ill, but is withheld from parents who do it out of love. Again, to take an extreme case, while authorities identified both James Holmes and Jared Loughner as needing help, as a result of HIPAA and FERPA their parents were kept in the dark. How can a family member, or in my case a daughter, ensure my loved one has transportation to an appointment if I don't know when the appointment is; or ensure she stays on medications if I am not told what the medicines are? Families are given the responsibility to provide care for mentally ill loved ones, but not the information needed to do so and so we watch helplessly as our loved one spirals into madness while our hands are tied. HR 3717 writes limited exclusions into HIPAA law so family/caregivers get the same information paid caretakers would receive.

We have to have community services that will let the most seriously ill into them.
We have to ensure that community services are in place to help the most seriously ill. Period. Right now, the ability to get into a program is inversely related to severity of illness. The least seriously ill go to the front of the line while the most seriously ill are sent to jails, prisons, the streets, and morgues. HR 3717 creates a secretary of mental health who can help insure that when community services are introduced, they focus on the most seriously ill. SAMHSA provides guidance to states on how to use Mental Health Block Grants. That direction often includes limiting resources to only those who can self-direct their own care, leaving the most seriously ill unserved...that excludes an entire population of people who need our help the most.

We have to stop funding non-evidence based programs and groups that impede care for the most seriously ill.
We have to ensure that programs are evidence based to improve a meaningful outcome in people with serious mental illness. Too many programs are measured by the claims of those who run them rather than independent investigators. Dr. Sally Satel testified that only four of the 288 programs in SAMHSA's National Registry of Evidence Based Practices focus on serious mental illness[5]. Further, SAMHSA seems to focus on soft measures for people much higher functioning like 'hope' and 'empowerment'. Those are very important, but we should also be measuring drops in suicide, homelessness, incarceration and other harder outcomes. SAMHSA is funding groups in California that are working to prevent implementation of policies that help the most seriously ill: opposing reforms of HIPAA, opposing implementation of Laura's Law, opposing preservation of adequate hospital beds. It is very hard for us to improve care for the most seriously ill in California when SAMHSA is providing funds to groups that oppose our efforts.

I urge you to pass HR 3717. It is wonderful and noble for Congress to want to improve the mental health of everyone, to help the higher functioning, but by doing so, we cannot ignore the most seriously ill and for too long we have. They are the **most vulnerable** and they need your help.

For over thirty years, my mother struggled with delusional ideas, grandiose thinking, paranoia, anxiety, and depression. She had left the family home and lived in an apartment in a state of total squalor, surrounded by stacks of newspapers and magazines dating back 15 years, rotten food, human feces, dead rodents. She continued to lash out and alienate herself from us even though we had always tried to do what was best for her.

I've spoken quite graphically about my mother today but you should also know she spoke 7 languages fluently, knew every opera libretto, and was a gifted pianist......she was passionate, creative, and loving....she was someone's daughter, someone's sister, someone's wife...and mother to 6 amazing children who were desperate for her presence and her love.

Her inability to acknowledge her illness **was not a choice**. It was a symptom that robbed us all of her amazing qualities...that robbed me of my mother. I am proud to be my mother's daughter. I inherited her passion, her creativity, her musicality, her outside the box thinking.

As her daughter who loved her, it was never easy as we were abandoned by an inadequate mental health system. My mother was failed by this system, my family was failed by this system, I was failed by this system.

Thank you.

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[1] Anosognosia is lack of awareness that an individual is ill. Anosognosia is the single largest reason why individuals with schizophrenia and bipolar disorder do not take their medications. It is caused by damage to specific parts of the brain, especially the right hemisphere. It affects approximately 50 percent of individuals with schizophrenia and 40 percent of individuals with bipolar disorder. The person believes that their delusions are real (e.g. the woman across the street really is being paid by the CIA to spy on him/her) and that their hallucinations are real (e.g. the voices really are instructions being sent by the President). Source: Dr. E. Fuller Torrey, Author, Surviving Schizophenia. Studies on anosognosia at http://mentalillnesspolicy.org/medical/anosognosia-studies.html

[2] The Shortage of Public Hospital Beds for the Mentally Ill, Report of the Treatment Advocacy Center, Arlington, VA 2005. Available at http://mentalillnesspolicy.org/imd/shortage-hosp-beds.pdf

[3] Governor Jerry Brown State Budget 2014. ""The composition of the patients served by DSH has changed greatly over time, with over 90 percent currently coming from the criminal justice system. In addition, the class action lawsuit (Coleman v. Brown) involving mental health care in state prisons has increased referrals from the Department of Corrections and Rehabilitation to DSH for inpatient treatment. The inmates referred to DSH tend to have a more violent history." Available at http://www.calnewsroom.com/wp-content/uploads/2014/01/FullBudgetSummary.pdf

[4] More Mentally Ill are in Jails and Prisons than Hospitals: A survey of the states. Treatment Advocacy Center. May 2010. Available at http://mentalillnesspolicy.org/NGRI/jails-vs-hospitals.html

[5] Testimony to House Energy and Commerce Subcommittee on Oversight and Investigations. Available at http://mentalillnesspolicy.org/samhsa/satel.5.22.13.samhsa.testimony.pdf

Reduction in harmful events when Laura's Law implemented in Nevada County

Key Indicator	Pre-AOT	Post-AOT	Improvement
Hospitalization	1404 days	748 days	46.7%
Incarceration	1824 days	637 days	65.1%
Homelessness	4224 days	1898 days	61.9%
Emergency Contacts	220 contacts	123 contacts	44.1%

Reduction in costs when Laura's Law implemented in Nevada County

Key Indicator	Pre-AOT	Post-AOT	Improvement
Hospitalization	$346,950	$133,650	$213,300
Incarceration	$78,150	$2,550	75,600

Summary: Nevada County gave individuals under court order access to services and found Laura's Law implementation saved $1.81-$.2.52 for ever dollar spent

Reduction in harmful events when Laura's Law implemented in Los Angeles County

Key Indicator	Percentage Decrease
Incarceration	Reduced 78%
Hospitalization	Reduced 86%
Hospitalization after AOT ended	Reduced 77%
Milestones of Recovery Scores	Increased

Reduction in costs when Laura's Law implemented in Los Angeles County

Laura's Law cut taxpayer costs 40 percent in Los Angeles.

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Source for Nevada County Data: Michael Heggarty, Behavioral Health Director, Nevada County. "The Nevada County Experience," Nov. 15, 2011.

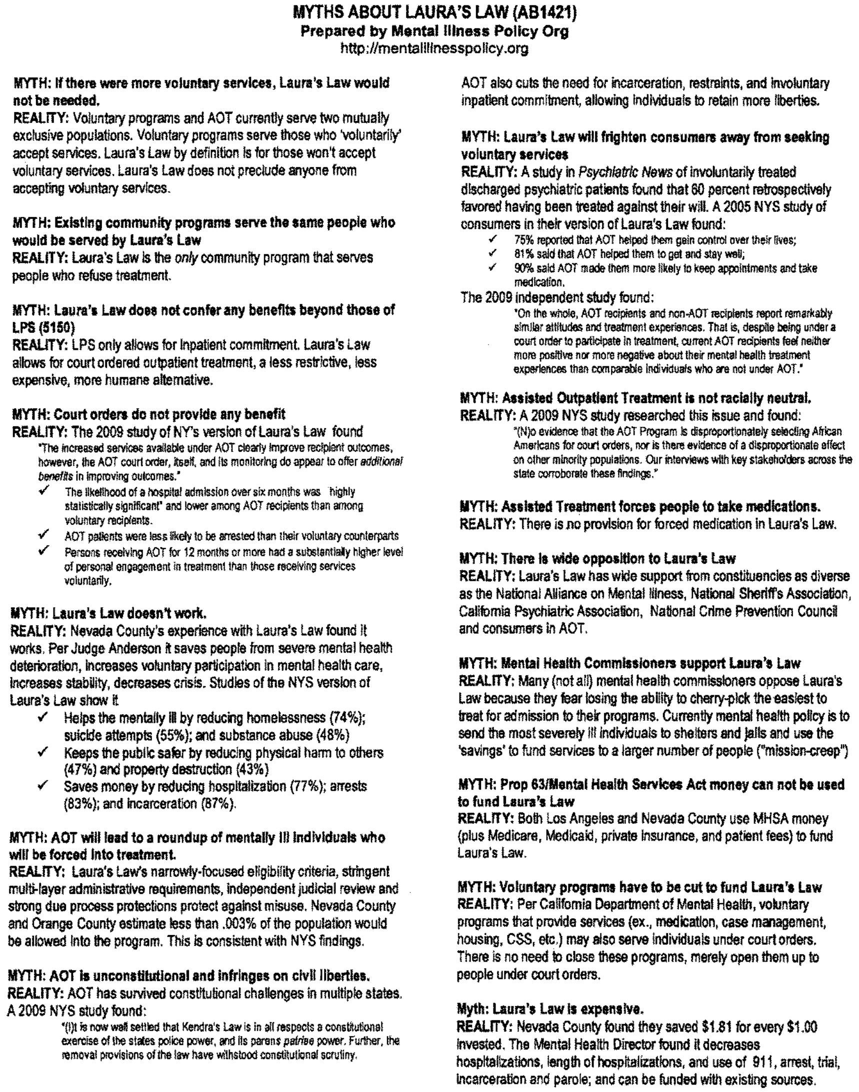
Source for Los Angeles County Data: County of Los Angeles. "Outpatient Treatment Program Outcomes Report" April 1, 2010 – December 31, 2010. Cost data from: Michael D. Antonovich, Los Angeles County Fifth District Supervisor, Los Angeles Daily News, December 12, 2011.

Prepared by Mental Illness Policy Org.
3/2012 http://lauras-law.org

10 Independent Kendra's Law Studies Show it works

Independent Study	Findings
May 2011 Arrest Outcomes Associated With Outpatient Commitment in New York State Bruce G. Link, et al. Ph.D. Psychiatric Services	For those who received AOT, the odds of any arrest were 2.66 times greater ($p<.01$) and the odds of arrest for a violent offense 8.61 times greater ($p<.05$) before AOT than they were in the period during and shortly after AOT. The group never receiving AOT had nearly double the odds (1.91, $p<.05$) of arrest compared with the AOT group in the period during and shortly after assignment."
October 2010: Assessing Outcomes for Consumers in New York's Assisted Outpatient Treatment Program Marvin S. Swartz, M.D., Psychiatric Services	Consumers who received court orders for AOT appeared to experience a number of improved outcomes: reduced hospitalization and length of stay, increased receipt of psychotropic medication and intensive case management services, and greater engagement in outpatient services.
February 2010 Columbia University. Phelan, Sinkewicz, Castille and Link. Effectiveness and Outcomes of Assisted Outpatient Treatment in New York State Psychiatric Services, Vol 61. No 2	Kendra's Law has lowered risk of violent behaviors, reduced thoughts about suicide and enhanced capacity to function despite problems with mental illness. *Patients given mandatory outpatient treatment - who were more violent to begin with - were nevertheless four times less likely than members of the control group to perpetrate serious violence* after undergoing treatment. Patients who underwent mandatory treatment reported higher social functioning and *slightly less stigma*, rebutting claims that mandatory outpatient care is a threat to self-esteem.
March 2005 N.Y. State Office of Mental Health "Kendra's Law: Final Report on the Status of Assisted Outpatient Treatment. "	**Danger and Violence Reduced** • 55% fewer recipients engaged in suicide attempts or physical harm to self • 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%. **Consumer Outcomes Improved** • 74% fewer participants experienced homelessness • 77% fewer experienced psychiatric hospitalization • 56% reduction in length of hospitalization. • 83% fewer experienced arrest • 87% fewer experienced incarceration. • 49% fewer abused alcohol • 48% fewer abused drugs **Consumer participation and medication compliance improved** • Number of individuals exhibiting good adherence to meds increased 51%. • The number of individuals exhibiting good service engagement increased 103%. **Consumer Perceptions Were Positive** • 75% reported that AOT helped them gain control over their lives • 81% said AOT helped them get and stay well • 90% said AOT made them more likely to keep appointments and take meds. • 87% of participants said they were confident in their case manager's ability. • 88% said they and case manager agreed on what is important to work on. **Effect on mental illness system** • **Improved Access to Services.** AOT has been instrumental in increasing accountability at all system levels regarding delivery of services to high need individuals. Community awareness of AOT has resulted in increased outreach to individuals who had previously presented engagement challenges to mental health service providers. • **Improved Treatment Plan Development, Discharge Planning, and Coordination of Service Planning.** Processes and structures developed for AOT have resulted in improvements to treatment plans that more appropriately match the needs of individuals who have had difficulties using mental health services in the past. • **Improved Collaboration between Mental Health and Court Systems.** As AOT processes have matured, professionals from the two systems have improved their working relationships, resulting in greater efficiencies, and ultimately, the conservation of judicial, clinical, and administrative resources. o There is now an organized process to prioritize and monitor individuals with the greatest need;

February 2010 Columbia University. Phelan, Sinkewicz, Castille and Link. Effectiveness and Outcomes of Assisted Outpatient Treatment in New York State Psychiatric Services, Vol 61, No 2	• Kendra's Law has lowered risk of violent behaviors, reduced thoughts about suicide and enhanced capacity to function despite problems with mental illness. • Patients given mandatory outpatient treatment - who were more violent to begin with - were nevertheless four times less likely than members of the control group to perpetrate serious violence after undergoing treatment. • Patients who underwent mandatory treatment reported higher social functioning and slightly less stigma, rebutting claims that mandatory outpatient care is a threat to self-esteem.
October 2010: Changes in Guideline-Recommended Medication Possession After Implementing Kendra's Law in New York, Alisa B. Busch, M.D Psychiatric Services	In all three regions, for all three groups, the predicted probability of an M(edication) P(ossesion) R(atio) ≥80% improved over time (AOT improved by 31–40 percentage points, followed by enhanced services, which improved by 15–22 points, and "neither treatment," improving 8–19 points). Some regional differences in MPR trajectories were observed.
October 2010 Robbing Peter to Pay Paul: Did New York State's Outpatient Commitment Program Crowd Out Voluntary Service Recipients? Jeffrey Swanson, et al. Psychiatric Services	In tandem with New York's AOT program, enhanced services increased among involuntary recipients, whereas no corresponding increase was initially seen for voluntary recipients. In the long run, however, overall service capacity was increased, and the focus on enhanced services for AOT participants appears to have led to greater access to enhanced services for both voluntary and involuntary recipients.
June 2009 D Swartz, MS, Swanson, JW, Steadman, HJ, Robbins, PC and Monahan J. New York State Assisted Outpatient Treatment Program Evaluation. Duke University School of Medicine, Durham, NC, June, 2009	We find that New York State's AOT Program improves a range of important outcomes for its recipients, apparently without feared negative consequences to recipients. • **Racial neutrality**: We find no evidence that the AOT Program is disproportionately selecting African Americans for court orders, nor is there evidence of a disproportionate effect on other minority populations. Our interviews with key stakeholders across the state corroborate these findings. **Court orders add value:** The increased services available under AOT clearly improve recipient outcomes, however, the AOT court order, itself, and its monitoring do appear to offer additional benefits in improving outcomes. • **Improves likelihood that providers will serve seriously mentally ill:** It is also important to recognize that the AOT order exerts a critical effect on service providers stimulating their efforts to prioritize care for AOT recipients. • **Improves service engagement:** After 12 months or more on AOT, service engagement increased such that AOT recipients were judged to be more engaged than voluntary patients. This suggests that after 12 months or more, when combined with intensive services, AOT increases service engagement compared to voluntary treatment alone. • **Consumers Approve**: Despite being under a court order to participate in treatment, current AOT recipients feel neither more positive nor more negative about their treatment experiences than comparable individuals who are not under AOT.
1999 NYC Dept. of Mental Health, Mental Retardation and Alcoholism Services. H. Telson, R. Glickstein, M. Trujillo, Report of the Bellevue Hospital Center Outpatient Commitment Pilot	• Outpatient commitment orders often assist patients in complying with outpatient treatment. • Outpatient commitment orders are clinically helpful in addressing a number of manifestations of serious and persistent mental illness. • Approximately 20% of patients do, upon initial screening, express hesitation and opposition regarding the prospect of a court order. After discharge with a court order, the majority of patients express no reservations or complaints about orders. • Providers of both transitional and permanent housing generally report that outpatient commitment help clients abide by the rules of the residence. More importantly, they often indicate that the court order helps clients to take medication and accept psychiatric services. • Housing providers state that they value the leverage provided by the order and the access to the hospital it offers.
1998 Policy Research Associates, Study of the NYC involuntary outpatient commitment pilot program.	• Individuals who received court ordered treatment in addition to enhanced community services spent 57 percent less time in psychiatric hospitals.



MYTHS ABOUT LAURA'S LAW (AB1421)

Prepared by Mental Illness Policy Org

http://mentalillnesspolicy.org

MYTH: If there were more voluntary services, Laura's Law would not be needed.
REALITY: Voluntary programs and AOT currently serve two mutually exclusive populations. Voluntary programs serve those who 'voluntarily' accept services. Laura's Law by definition is for those won't accept voluntary services. Laura's Law does not preclude anyone from accepting voluntary services.

MYTH: Existing community programs serve the same people who would be served by Laura's Law
REALITY: Laura's Law is the *only* community program that serves people who refuse treatment.

MYTH: Laura's Law does not confer any benefits beyond those of LPS (5150)
REALITY: LPS only allows for inpatient commitment. Laura's Law allows for court ordered outpatient treatment, a less restrictive, less expensive, more humane alternative.

MYTH: Court orders do not provide any benefit
REALITY: The 2009 study of NY's version of Laura's Law found

> "The increased services available under AOT clearly improve recipient outcomes, however, the AOT court order, itself, and its monitoring do appear to offer *additional benefits* in improving outcomes."

- ✓ The likelihood of a hospital admission over six months was "highly statistically significant" and lower among AOT recipients than among voluntary recipients.
- ✓ AOT patients were less likely to be arrested than their voluntary counterparts
- ✓ Persons receiving AOT for 12 months or more had a substantially higher level of personal engagement in treatment than those receiving services voluntarily.

MYTH: Laura's Law doesn't work.
REALITY: Nevada County's experience with Laura's Law found it works. Per Judge Anderson it saves people from severe mental health deterioration, increases voluntary participation in mental health care, increases stability, decreases crisis. Studies of the NYS version of Laura's Law show it

- ✓ Helps the mentally ill by reducing homelessness (74%); suicide attempts (55%); and substance abuse (48%)
- ✓ Keeps the public safer by reducing physical harm to others (47%) and property destruction (43%)
- ✓ Saves money by reducing hospitalization (77%); arrests (83%); and incarceration (87%).

MYTH: AOT will lead to a roundup of mentally ill individuals who will be forced into treatment.
REALITY: Laura's Law's narrowly-focused eligibility criteria, stringent multi-layer administrative requirements, independent judicial review and strong due process protections protect against misuse. Nevada County and Orange County estimate less than .003% of the population would be allowed into the program. This is consistent with NYS findings.

MYTH: AOT is unconstitutional and infringes on civil liberties.
REALITY: AOT has survived constitutional challenges in multiple states. A 2009 NYS study found:

> "(I)t is now well settled that Kendra's Law is in all respects a constitutional exercise of the states police power, and its parens *patriae* power. Further, the removal provisions of the law have withstood constitutional scrutiny. AOT also cuts the need for incarceration, restraints, and involuntary inpatient commitment, allowing individuals to retain more liberties.

MYTH: Laura's Law will frighten consumers away from seeking voluntary services
REALITY: A study in *Psychiatric News* of involuntarily treated discharged psychiatric patients found that 60 percent retrospectively favored having been treated against their will. A 2005 NYS study of consumers in their version of Laura's Law found:

- ✓ 75% reported that AOT helped them gain control over their lives;
- ✓ 81% said that AOT helped them to get and stay well;
- ✓ 90% said AOT made them more likely to keep appointments and take medication.

The 2009 independent study found:

> "On the whole, AOT recipients and non-AOT recipients report remarkably similar attitudes and treatment experiences. That is, despite being under a court order to participate in treatment, current AOT recipients feel neither more positive nor more negative about their mental health treatment experiences than comparable individuals who are not under AOT."

MYTH: Assisted Outpatient Treatment is not racially neutral.
REALITY: A 2009 NYS study researched this issue and found:

> "(N)o evidence that the AOT Program is disproportionately selecting African Americans for court orders, nor is there evidence of a disproportionate effect on other minority populations. Our interviews with key stakeholders across the state corroborate these findings."

MYTH: Assisted Treatment forces people to take medications.
REALITY: There is no provision for forced medication in Laura's Law.

MYTH: There is wide opposition to Laura's Law
REALITY: Laura's Law has wide support from constituencies as diverse as the National Alliance on Mental Illness, National Sheriff's Association, California Psychiatric Association, National Crime Prevention Council and consumers in AOT.

MYTH: Mental Health Commissioners support Laura's Law
REALITY: Many (not all) mental health commissioners oppose Laura's Law because they fear losing the ability to cherry-pick the easiest to treat for admission to their programs. Currently mental health policy is to send the most severely ill individuals to shelters and jails and use the 'savings' to fund services to a larger number of people ("mission-creep")

MYTH: Prop 63/Mental Health Services Act money can not be used to fund Laura's Law
REALITY: Both Los Angeles and Nevada County use MHSA money (plus Medicare, Medicaid, private insurance, and patient fees) to fund Laura's Law.

MYTH: Voluntary programs have to be cut to fund Laura's Law
REALITY: Per California Department of Mental Health, voluntary programs that provide services (ex., medication, case management, housing, CSS, etc.) may also serve individuals under court orders. There is no need to close these programs, merely open them up to people under court orders.

Myth: Laura's Law is expensive.
REALITY: Nevada County found they saved $1.81 for every $1.00 invested. The Mental Health Director found it decreases hospitalizations, length of hospitalizations, and use of 911, arrest, trial, incarceration and parole; and can be funded with existing sources.

by HERSCHEL HARDIN

. . a West Vancouver author and consultant. He was a director of the B.C. Civil Liberties Association from 1965 to 1974, and has been involved in defence of liberty and free speech through his work with Amnesty International. One of his children has schizophrenia.

Uncivil liberties

Far from respecting civil liberties, legal obstacles to treating the mentally ill limit or destroy the liberty of the person

THE PUBLIC is growing increasingly confused by how we treat the mentally ill.

More and more, the mentally ill are showing up in the streets, badly in need of help. Incidents of illness-driven violence are reported regularly — incidents which common sense tells us could easily have been avoided. And this is just the visible tip of the greater tragedy — of many more sufferers deteriorating in the shadows and, often, committing suicide.

People ask in perplexed astonishment: "Why don't we provide help and treatment, when the need is so obvious?" Yet every such cry of anguish is met with the rejoinder that unrequested intervention is an infringement of civil liberties.

This stops everything. Civil liberties, after all, are a fundamental part of our democratic society.

The rhetoric and lobbying results in legislative obstacles to timely and adequate treatment, and the psychiatric community is cowed by the anti-treatment climate produced.

Here is the Kafkaesque irony: Far from respecting civil liberties, legal obstacles to treatment limit or destroy the liberty of the person.

The best example concerns schizophrenia. The most chronic and disabling of the major mental illnesses, schizophrenia involves a chemical imbalance in the brain, alleviated in most cases by medication. Symptoms can include confusion; inability to concentrate, to think abstractly, or to plan; thought disorder to the point of raving babble; delusions and hallucinations; and variations such as paranoia.

Untreated, the disease is ravaging. Its victims cannot work or care for themselves. They may think they are other people — usually historical or cultural characters such as Jesus Christ or John Lennon — or otherwise lose their sense of identity. They find it hard or impossible to live with others, and they may become hostile and threatening. They can end up living in the most degraded, shocking circumstances, voiding in their own clothes, living in rooms overrun by rodents — or in the streets. They often deteriorate physically, losing weight and suffering corresponding malnutrition, rotting teeth and skin sores. They become particularly vulnerable to injury and abuse.

TORMENTED by voices, or in the grip of paranoia, they may commit suicide or violence upon others. (The case of a Coquitlam boy who killed most of his family is only one well-publicized incident of such delusion-driven violence.) Becoming suddenly threatening or bearing a weapon, say a knife — because of a delusionally perceived need for self-protection — the innocent schizophrenic may be shot down by police.

Depression from the illness, without adequate stability — often as the result of premature release — is also a factor in suicides.

Such victims are prisoners of their illness. Their personalities are subsumed by their distorted thoughts. They cannot think for themselves and cannot exercise any meaningful liberty.

The remedy is treatment — most essentially, medication. In most cases, this means involuntary treatment because people in the throes of their illness have little or no insight into their own condition. If you think you are Jesus Christ or an avenging angel, you are not likely to agree that you need to go to hospital.

Anti-treatment advocates insist that involuntary committal should be limited to cases of imminent physical danger — instances where a person is going to do serious bodily harm to himself or somebody else.

But the establishment of such "dangerousness" usually comes too late — a psychotic break or loss of control, leading to violence, happens suddenly. And all the while, the victim suffers the ravages of the illness itself, the degradation of life, the tragic loss of individual potential.

The anti-treatment advocates say: "If that's how people want to live (babbling on a street corner, in rags), or if they wish to take their own lives, they should be allowed to exercise their free will. To interfere — with involuntary committal — is to deny them their civil liberties." As for the tragedy that follows from this dictum, well, "That's the price that has to be paid if society is to maintain its civil liberties."

Whether or not anti-treatment advocates actually voice such opinions, they seem content to sacrifice a few lives here and there to uphold an abstract doctrine. Their intent, if noble, has a chilly, Stalinist justification — the odd tragedy along the way is warranted to ensure the greater good.

THE NOTION that this doctrine is misapplied escapes them. They merely deny the nature of the illness.

Health Minister Elizabeth Cull appears to have fallen into the trap of this juxtaposition. She has talked about balancing the need for treatment and civil liberties, as if they were opposites. It is with such a misconceptualization that anti-treatment lobbyists promote legislation loaded with administrative and judicial obstacles to involuntary committal.

The result, inadvertently for Cull, Attorney-General Colin Gabelmann (as regards guardianship legislation) and the government, will be a certain number of illness-caused suicides every year, just as surely as if those people were lined up annually in front of a firing squad. Add to that the broader ravages of the illness, and keep in mind the manic-depressives who also have a high suicide rate.

A doubly ironic downstream effect: the inappropriate use of criminal prosecutions against the mentally ill, and the attendant cruelty of committal to jails and prisons rather than hospitals. B.C. Corrections once estimated that almost one-third of adult offenders and close to one-half of young offenders in the provincial corrections system have a diagnosable mental disorder.

Clinical evidence has now indicated that allowing schizophrenia to progress to a psychotic break lowers the possible level of future recovery, and subsequent psychotic breaks lower that level further — in other words, the cost of withholding treatment is permanent damage.

Meanwhile, bureaucratic roadblocks, such as time-consuming judicial hearings, are passed off under the cloak of "due process" — as if the illness were a crime with which one is being charged and hospitalization for treatment is a punishment. Such cumbersome restraints ignore the existing adequate safeguards — the requirement for two independent assessments and a review panel to check against overlong stays.

How can so much degradation and death — so much inhumanity — be justified in the name of civil liberties? It cannot.

The opposition to involuntary committal and treatment betrays a profound misunderstanding of the principle of civil liberties. Medication can free victims from their illness — free them from the Bastille of their psychoses — and restore their dignity, their free will and the meaningful exercise of their liberties. ❑

Mr. PITTS. The chair thanks the gentlelady and now recognizes Dr. Shern five minutes for his opening statement.

STATEMENT OF DAVID L. SHERN

Mr. SHERN. Thank you, Mr. Pitts, members of the committee. I am the Interim President and CEO of Mental Health America, which is the Nation's oldest mental health advocacy organization. We are 105 years old this year. We were founded by a person who had bipolar illness and have throughout our history stood very firmly for the full inclusion of people with mental illnesses in every aspect of American life. We have 240 affiliates around the country, approximately, and are very concerned with America's mental health from a public health perspective.

Prior to joining Mental Health America, I was a tenured Professor and Dean at the University of South Florida and a mental health researcher, a psychologist by training, and I spent my professional career really studying systems of care for people with severe mental illnesses, and of particular relevance, I think, for our discussion today was a program, an NIMH-funded program that we conducted in New York City, an experimental program using psychiatric rehabilitation technology to engage and serve persons with severe mental illnesses who are homeless, living on the streets of New York City, about 60 percent of whom also had very serious addiction disorders. We were able through the use of peer counselors who are involved in the program and a very well understood technology, psychiatric rehabilitation technology developed by Boston University to engage this very difficult to treat, most in need group of individuals. We did that by emphasizing the fact that they had choices in terms of how they could organize their recovery and empowered them to express those choices and empowered our team, our treatment team, to enact those choices.

Through that process, we successfully housed the majority of clients. We significantly reduced their level of psychiatric symptomatology. We improved their quality of life.

The important point is, I thought about these issues a lot, and it is clear to me that we have technologies that can be used to engage individuals in care. We don't always do it, but those technologies are available to us and our challenge is to try to implement them more effectively.

I am also a family member. I think everyone here is a family member. I have a feeling if we queried the committee, we would find out that there is not one degree of separation between many of us and a family member who has a mental health problem. My nephew had severe bipolar disorder, particularly when he was in high school, and even though I knew all the people in the United States who developed the evidence-based practices for this because of the inadequate system of care, in this case in Pueblo, Colorado, we couldn't get Kyle what he needed. Fortunately, my family had the resources to get him into residential care and he is doing fine now, but we went through a very difficult time, a time when he was confused about what was going on with him and so I am very sensitive to these issues.

The reason that I left academia and entered advocacy was to try to close this gap between what we know and what is routinely available to people, and there are many aspects, as many of you have commented already, many aspects of this legislation that are very important and that will seek to do that, to expand coverage, and as many people have expressed, we are very enthusiastic and supportive of those.

There are, however, some aspects about which we are very concerned. We are concerned with the emphasis on assisted outpatient treatment. It is very clear to us that the issue is having a full engagement-oriented system of care for individuals and making those services available to those individuals. We are concerned with expansion of the IMD exclusion, focusing only on one type of care when we realize, as Dr. Arthur Evans testified last week, that is in fact a continuum of care which is most important.

We are concerned with what we conceive as an attack on the protection and advocacy system and what we conceive as some very fundamental misunderstandings about the role of the Substance Abuse and Mental Health Services Administration in leading the Nation's health. From our perspective, SAMHSA has led every major mental health reform during the last 50 years. Is our system what we think it should be? No, it is fragmented, it is broken and it is not responding to people. Do we have the technology to make a difference? Yes, we do. Are we implementing that technology? No, we are not. There are several aspects of this bill which will help with that. However, there are some premises and some assumptions that are very concerning for us and that we feel ultimately will damage the system and will make it in fact more difficult for people to access the services that they need.

We have made big progress with the Parity Act and enacting that as part of the Affordable Care Act, which was bipartisanly adopted by the Senate Finance Committee in the initial markup of the bill. It is a chance for us to live into the possibility of that Act to get people the services that they need.

Thank you, Mr. Chairman.

[The prepared statement of Mr. Shern follows:]

Statement of David L. Shern, Ph.D.
President and CEO, Mental Health America
Before the Health Subcommittee, Energy & Commerce Committee
Hearing on Helping Families in Mental Health Crisis Act of 2013
April 3, 2014

Mr. Chairman and members of the Committee, I am Dr. David Shern, Interim President and CEO of Mental Health America. Mental Health America is the nation's oldest advocacy organization concerned with all aspects of mental health and mental illness. From our founding, we have worked to not only improve the treatment conditions for persons with mental illnesses, but also to prevent and cure mental health conditions. Today, we have a formidable scientific basis for prevention and treatment of mental health and substance use conditions. While much is yet to be discovered in these areas, our current challenge is to apply what we know can work, which includes state of the art treatment and supports with the full involvement of persons with these illnesses in all aspects of their care. MHA has 228 affiliates located throughout the U.S.

I am a research psychologist by training and was Dean and a Professor at the University of South Florida, directing a large mental health research institute before joining MHA in 2006. I have spent my career studying systems of care for persons with severe mental illnesses (SMI), including persons who are most in need of care. I have directed federally funded research projects that have investigated the optimal ways to serve individuals who have not been well served traditionally by our public mental health system, including homeless, street dwelling individuals with severe illnesses and, often, co-occurring addictions. This later program integrated treatment and rehabilitation services with a strong emphasis on consumer choice and program accountability for the outcomes achieved by persons who were served. It has evolved into a national model housing program for persons who are homeless and have severe illness—Pathways to Housing—that is now a national model for an evidence-based program to serve this population. Therefore, I have deep experience in many of the issues addressed in this legislation and with alternative approaches for serving individuals who many would characterize as difficult to treat. It has been a great honor to lead MHA for most of the last eight years in an attempt to better bridge the gap between what we know can help individuals with SMI and what is routinely available to them in communities throughout this nation.

In addition, I am a family member of a person who had a severe mental illness. My nephew has bipolar illness that was particularly difficult during his late high school years. Even with the best connections in the US, we were unable to get him the services that he needed in his home town and he required out of state placement in a residential treatment facility. All has turned out well for him at this point but I have a strong personal connection to the difficulty in obtaining the care that is needed.

In my case there was an extensive evidence base regarding the care that my nephew needed but evidence-based care was not available for him. There remains much to be done to adequately implement what we know could make a big difference in the lives of persons with these conditions and the people who care about them. As such, we agree with the premise of the legislation that our current systems are broken and in urgent need of repair and we congratulate Representative Murphy for his efforts to address these problems through federal legislation. It is a bold attempt to address many aspects of our current system that are in need of repair. It includes many laudatory features such as the reauthorization of the Mentally Ill Offender Treatment and Crime Reduction Act, the Garret Lee Smith suicide prevention program, and the National Child Traumatic Stress Network, and enhancing support for community-based behavioral health programs and fostering health information technology, increased funding for research, grants for integration of care, education in the schools and justice system, codifying anti-depressants and anti-psychotics as protected classes. All these steps will undoubtedly improve the infrastructure and programming in mental health.

Finding an Effective Balance of Interventions, Services and Supports: However, there are other aspects of the bill that are of great concern to MHA and many other advocacy organizations. We strongly believe that some aspects of the legislation, while well intended, will ultimately result in damage to the system and the people served by these systems. While we share the ends sought by the legislation, we differ on the several of the means proposed to achieve these ends. The issue is finding an effective balance of interventions, services, and supports

A bit of history of the American mental health system might help to frame our concerns. There was a time, not long ago, where the leading psychiatric thinking held that receiving a diagnosis of schizophrenia was tantamount to a death sentence. It was asserted that the course of illness was inexorably one of increasing deterioration—moving from positive symptoms of delusions, hallucinations, agitation to negative symptoms of emotional withdrawal, non-responsiveness to a vegetative state. These observations were largely drawn from individuals who spent decades in psychiatric hospitals. Starting in the 1970s and 80s, long-term follow-up studies of individuals who were released from state hospitals were conducted with startling results. The best known of these was conducted by Courtney Harding at Yale who obtained information from over 90 percent of a group of long-term patients released from the Vermont State Hospital. What Harding found was a group of largely recovered individuals— the majority of whom were indistinguishable from other 'normal' community residents. These findings have now been replicated over 10 times with differing samples of persons with schizophrenia. Clearly, our science regarding the course of illness was wrong and based on biased observations of persons who were institutionalized. In part, we were seeing the effects of the environments in which people were living and not the inexorable effects of their illness.

Recovery—Designing Services that are Person-Focused and Skill-Based: These findings began to change everything we knew about the possibility of recovery from severe mental illness. Harding and colleagues went on to further study the difference in outcomes between Maine and Vermont patients with Vermont having a more rehabilitative-oriented system of care than Maine. She found that long-term patients who resided in Vermont recovered more quickly and completely than individuals in Maine suggesting that the organization and delivery of services made a difference in facilitating recovery.

Importantly, this later study suggested that designing services that were person- focused and skill-based could make a big difference in the outcomes that individuals achieved.

It is well known today that the movement from large, institutionally based care to community based care called deinstitutionalization was fundamentally flawed. The vision of community integration that inspired the movement and the horrible circumstances of large, custodial institutions that compelled it were, unfortunately, not sufficient to achieve the outcomes that were desired for persons with severe mental illnesses. We now know that the lack of adequate individualized and coordinated community supports including housing, income, educational and employment supports as well as access to effective treatment services, including crisis support and acute inpatient care led to the horrible outcomes of homelessness and incarceration that are addressed in the proposed legislation. We now know what is needed to effectively serve individuals with the most severe mental illnesses, many of whom have addictions. Our challenge is to successfully implement this knowledge in a fragmented, underfunded treatment and support system. I think that there is little disagreement here.

How to Implement Knowledge—Need for an Adequately Funded Treatment and Rehabilitative System: Where we disagree is how best to achieve these ends. From our perspective, the proposed legislation misinterprets our history and undermines many of the system components that have contributed to progress. It seeks judicial remedies for what are clinical challenges. What we need is an adequately funded treatment and rehabilitative system in which identified points of system accountability are established for individuals who are most in need of care. One that assertively engages these individuals where they are—both physically and psychologically—and helps them craft a recovery plan that is responsive to their individual needs and circumstances. Given the historical patterns of discrimination against persons with mental illnesses, this system must also protect their rights and assure that they have a voice in designing the systems of care to meet their needs. A witness at the Committee's hearing last week—Dr. Arthur Evans—argued that we need a comprehensive strategy for people in psychiatric crisis, that the hospital must be seen in the context of the larger community support, and the number and use of hospital beds is largely driven by the lack individualized, coordinated, comprehensive community-based services and supports.

Improve Protection and Advocacy Rather than Dismantle: Provisions in the proposed legislation that seek to undermine the Protection and Advocacy (PAIMI) function by dramatically reducing its funding do not serve these ends. While the system surely can be improved and might benefit from the use of more alternative dispute resolution techniques like psychiatric advanced directives and mediation-oriented dispute resolution, the wholesale abandonment of the PAIMI function would be disastrous in our current systems. Improved accountability and new technologies for this system are needed, not dismantling it.

Similarly, elimination of the IMD exclusion in Medicaid without maintenance of efforts provisions for the states could potentially incentivize expensive inpatient care settings at the expense of community alternatives. We have long known that an organized system of care is needed and, as Dr. Evans noted in earlier testimony to this committee, the need for inpatient beds is largely dependent upon the number and type of community treatment alternatives that are available. With an adequately funded crisis system, respite housing, peer supports, rehabilitative services and, importantly, assertive outreach to individuals who are most in need with single points of responsibility for their care and outcomes—as has been achieved in New York—inpatient treatment can be used most effectively. Inpatient care can help stabilize individuals who are acutely ill, keep them and others safe and rapidly return them to their communities with adequate follow-up so that they can resume their life goals and community participation. Adding resources to the most expensive and restrictive element in the system without an overall plan for designing a state of the art system of care including safe alternatives to inpatient care would be irresponsible and very expensive - particularly in the light of Medicaid expansion with 100 percent federal funding for expansion services. A CBO score on this provision would be helpful in fully understanding its fiscal impact. Insert need for fiscal project for modifying the exclusion.

Additionally, current provisions in the ACA (Section 2707) are examining 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. It only seems sensible to await the results of this demonstration before making further changes to the IMD exclusion.

Need Adequate, Consumer-Focused System of Care: It is an adequate, consumer-focused system of care that we know will make a difference in the outcomes experienced by persons with severe mental illness. The Assisted Outpatient Treatment (AOT) provisions in the proposed legislation would condition receipt of mental health block grant funds on the successful implementation of this coercive mechanism in each of the states. The logic here is that compelling persons most in need into care will improve their outcomes. The evidence to support this assertion is thin. The best research indicates that it is only when adequate systems of care exist that AOT interventions have shown positive outcomes. Additionally, none of the research to date has estimated the number of persons who avoid any contact with the treatment system as a result of the potential coercion. My own experience with the homelessness treatment program I mentioned earlier in my testimony indicates that this is a real concern. Our treatment systems should be welcoming rather than frightening. Most states currently have an AOT provision available but it is rarely effectively used because it cannot create a system of care by ordering treatment. Clearly, we need to concentrate on the development of the system and compelling people into a non-existent system makes no sense. Punishing states by removing resources that could be used to develop such a system (i.e. the block grant) makes even less sense.

Incorrectly Linking Mental Illness to Violence Deters People from Seeking Help: Much of the recent focus on AOT was motivated by recent mass shootings and the perceived link between violence and mental illness. It has been known for many years that there is no simple link between mental illnesses and violence—except that persons with severe mental illnesses are much more likely to be the victim of violence than other individuals. We now know from careful epidemiological research that there are a small group of individuals with a very specific symptom cluster that are more likely to exhibit some violent behavior broadly defined to include pushing or hitting others. When these symptoms are treated the risk of violence diminishes. Dr. Jeff Swanson at Duke University who conducted this work and who is generally seen as a national expert of violence and mental illness estimates that if all mental illnesses were cured we would see a 4 percent reduction in violence. Clearly, 96 percent of the problem is not related to diagnosable mental illnesses. Similarly, in a systematic examination of 34 instances of mass shootings perpetrated by adolescents between 1958 and 1999, Meloy and colleagues estimated that the common characteristics among the shootings involved sex (male), social isolation, substance use, a preoccupation with gun and being a victim of bullying. Less than a quarter of the shooters had a documented psychiatric history and only about 6 percent were psychotic at the time of the shootings. The best predictor of violence is violence. If we want to effectively address these issues we should directly target evidence of violent behavior. Linking mental illnesses and violence will do little to address the overall problems of violence and only serves to further stigmatize mental health conditions and to depress help seeking.

This is not to say that persons who are a danger to self or others should not receive priority access to care. An assertive outreach program to individuals who are identified at significant risk for harmful behaviors to either self or others that involves concerned family and friends as key treatment team allies is what is needed. Targeted outreach and access to a range of treatments and supports— including inpatient care when it is needed—would go a long way toward better serving persons with SMI, keeping communities and individuals safe as well as promoting recovery.

SAMHSA Has Improved Treatment System: From our perspective the Substance Abuse and Mental Health Services Administration (SAMHSA) has led in efforts to develop these systems for both adults and children. The proposed legislation includes changes to SAMHSA. Some assert that the agency's priorities are misguided and resources are not spent effectively. Further, some feel that the agency promotes a particular agenda that encourages individuals to forgo traditional treatment strategies including medication. From our perspective, none of these allegations are correct.

SAMHSA and its progenitor Centers in the NIMH, NIDA and NIAAA prior to their separation in 1993 have been responsible for many of the treatment system improvements experienced during the last 40 years. It was the SAMHSA Community Support Program of the 1970's that first brought attention to the plight of adults with severe mental illnesses in the community. This program realized the critical nature of case management services, the need for income, employment and housing supports and the needs of persons who were trans-institutionalized in nursing, boarding and assisted living facilities following their discharge from state hospitals. Similarly, it was SAMHSA that first focused systematically on the needs of children with severe emotional problems through the CAASP program that incubated the successful national Systems of Care Initiatives supported by Congressional appropriations. It was SAMHSA that first documented the rates of mental illnesses among persons who were homeless and launched a series of demonstration programs that have been shown to be effective in engaging, housing and serving these individuals. It was SAMHSA, following creation of the Block Grants in 1980, which encouraged states to more effectively target funds toward the adults with severe mental illnesses and children with severe emotional disturbance through the states' new leverage with the Community Mental Health Centers. It was SAMHSA that supported the need for integrated substance use and mental health services through a series of initiatives targeted at individuals with dual diagnosis. It was SAMHSA that partnered with HRSA to launch a national effort to better coordinate primary care and specialty mental health services in community health and mental health clinics to address the tragedy of premature mortality among persons with severe mental illnesses. In short, these exemplar programs strongly underline SAMHSA's historical and continuing leadership to address the nation's mental health needs.

How to Best Coordinate Supports and Services: In their recent book – Better but Not Well –Richard Frank and Sherrie Glied noted that we have made significant improvements in the treatment of individuals with severe mental illnesses and that much of the improvement is attributable to income support and housing programs as adjunctive to mental health treatment. Something we've known for nearly a century is that mental illnesses impoverish individuals. They strike individuals as they are launching their adult life and, owing to the lack of access to effective treatment, can sentence an individual to a life of poverty with the constant risk of homelessness. The income and housing support programs along with the expansion of Medicaid services to better meet the treatment needs of individuals has had a beneficial impact for persons with severe mental illnesses. SAMHSA, along with the advocacy and professional community, has had a key role in promoting these efforts within the federal government. In noting that the needs of individuals with SMI involve more than treatment involving several federal departments, Frank and Glied proposed the establishment of a White House Office charged with coordinating the varying federal programs that impact persons with SMI. We would support the development of such an office.

The current legislation proposes establishing an Assistant Secretary for Mental Health and Substance Use Disorders in HHS with the goal of better coordinating the HHS programs impacting persons with mental illnesses. We would not oppose such an initiative if both mental health and substance use programming were overseen by such an office and particularly like the Policy Laboratory as part of the office. However, since the SAMHSA Administrator now reports directly to the Secretary, we see little advantage in creating such an office. Our impression is that the interagency coordination with HHS and across government departments has been improving during the last several years and mechanisms to further stimulate collaboration are desirable. Given the large number of departments outside HHS that have important impact on the public's mental health we would enthusiastically support a White House office.

Other changes suggested for SAMHSA would create additional Congressional oversight for their programs and statutorily increase the involvement of licensed mental health professionals in the oversight and functioning of the agency. Additionally, the legislation seeks to limit services supported by SAMHSA to those that have an evidence base. As noted earlier, the problems of persons with SMI involve more than mental health treatment services. Appropriate involvement of expertise from each of the sectors relevant to the well-being of adults with SMI is certainly appropriate including expertise in justice, education, housing and labor among others. Perhaps most importantly, the voices of persons served by the system, both primary consumers and concerned family members, are of critical importance. Prescribing levels of licensed mental health professional involvement will make it more difficult to practically obtain the broad range of expertise needed for SAMHSA programs. We would propose either eliminating the 50 percent requirements or reducing the percentage to 25 percent. We would propose that 51 percent of any advisory group be composed of mental health consumers and family members who, obviously, could also be mental health professionals or persons with expertise in allied areas. This is consistent federal policies starting with the Developmental Disabilities Services and Assistance act of 1970.

Peer-Delivered Interventions Hold Great Promise: As noted earlier, SAMHSA has played a key role in stimulating the development and testing of innovative treatment and support programs. Programs focused on engagement in care with the use of innovative strategies including peer support are among these innovative programs. Peer delivered interventions hold great promise in increasing adherence to meaningful recovery plans as well as addressing the emerging workforce challenges that we will have in health care overall. We feel that it is critical that SAMHSA maintain the ability to help support these programs with rigorous evaluations to determine their effectiveness. Restricting programs to those which already have an evidence base will have a chilling effect on the field since SAMHSA is one of the only sources of funding for innovation that may then be more rigorously tested by NIMH, NIDA, NIAAA and other entities once some evidence base and program specifications are developed.

Finally, we heartily endorse the sense of the legislation that meaningful involvement of concerned family members and others in the individual's social networks is an essential feature of any treatment and recovery plan. We greatly share the concerns of family members of people with severe mental illness, including those who have testified before the Committee. It is clear that no one knows more about a person's situation than the individual and their close family members and friends. But privacy of medical information is also of primary concern. As we understand HIPAA, it permits the sharing of information with the consent of the individual and in emergency or crisis situations. We would support public education efforts to better inform practitioners regarding current HIPAA regulations, including codification of the Office of Civil Rights' interpretation of access to medical information. We urge that people be consulted about and have a meaningful opportunity to oppose any release of their personal medical information.

Given the comprehensive nature of the proposed legislation we think that it provides an excellent opportunity to further strengthen the implementation of the Mental Health Parity and Addiction Equity Act of 2008. We suggest that the legislation call for an organized effort by the Department of Labor in conjunction with HHS to collect information on compliance with MHPAEA that results in annual transparent, de-identified reports of all enforcement actions and an updated compliance guide that is easily accessible to plans, employers, employees, etc.

We therefore applaud the committee for this important work and especially Representative Murphy for his leadership in this matter. As is clear from our comments, we share a common vision for what is needed to improve care: A person-centered approach with a full range of treatments and supports to facilitate an individual's recovery from severe mental illness. Successful engagement in care requires an acceptable and accessible service system focus on the individual needs and desires and informed by meaningful family involvement.

Mr. PITTS. The Chair thanks the gentleman and now recognizes Ms. Jensen 5 minutes for an opening statement.

STATEMENT OF NANCY JENSEN

Ms. JENSEN. My name is Nancy Jensen, and I am the author of "The Girl Who Cried Wolf," which tells the story of my lived experienced as a person with mental illness and a survivor of the terrible place called Kaufman House in Newton, Kansas.

The story of Kaufman House vividly shows why parts of this bill destroying the funding and effectiveness of both PAIMI and recovery programs must be removed. This bill slashes funding for PAIMI's program and takes away their ability to combat evil and protect the rights of people with mental illness including the right to choose their treatment.

If this bill is law, the Kaufman House would still be terrorizing, abusing and enslaving people with mental illness. As a former resident, I know how terrible Kaufman House was. They called what they were doing therapy. It was not therapy. It was sexual and emotional abuse. The Kaufmans forced their so-called patients to be nude and do bizarre acts, sex acts, while they videotaped it. I was forced to be naked, to sleep on a filthy floor and use a bucket for a toilet. I was degraded and told I should never get married, never have a child, never join a church, and that I would never get a job. Well, as a proudly married mother with both faith in God and a job, I proved Kaufman wrong.

The PAIMI program shut down this house of horrors when no one else would or could. The PAIMI program freed my friends and helped get us justice. I was the first former resident to tell the State about the evil. Eleven other Kansans made reports after me but the State did absolutely nothing.

How did PAIMI programs shut down Kaufman House when the State adult protective services could not? Well, first, the PAIMI Act gives protection and advocacy agencies powers and independence to gain access in places like Kaufman House to investigate and shut them down. Without a court order, the APS was turned away. Second, PAIMI programs provided the P&A enough funding so that it could properly investigate the Kaufmans, and PAIMI freed us and got us the right treatment and then pressed for policy changes. Third, and perhaps the most important, with PAIMI, the victim is the client. The client is in charge. With the APS, they serve the interests of the provider and the State.

Long story short, thanks to PAIMI and its special powers and funding, the Kaufman House was shut down and we obtained the right type of treatment, and Arlan and Linda Kaufman were found guilty of over 60 charges. The Kaufmans are in prison today and I am here testifying. How cool is that?

This bill also takes away the PAIMI program's ability to educate policymakers. The PAIMI program worked with me as a survivor to change policy so future Kaufman Houses can never happen again. Licenses are now required, guardianship laws are fixed, and now there is an abuse and neglect unit.

PAIMI does not just help victims of abuse. This bill makes it harder for people with mental illness to find housing, employment and education. It prevents individuals with mental illness from receiving the treatment they choose.

Another important lesson from Kaufman House is the need for recovery programs like alternatives conference. You must have recovery programs to have recovery.

Finally, I believe this bill is misnamed. The Helping Families in Mental Crisis Act? Well, I want to respectfully point out to the subcommittee that the focus needs to be on helping the individual with mental illness and crisis and through recovery. Yes, families are really important support but the focus needs to be on the person and their recovery.

Thank you.

[The prepared statement of Ms. Jensen follows:]

Nancy Jensen, Person with Lived Mental Health Experiences and Author
Testimony on HR 3717 before the House Energy and Commerce Subcommittee on Health

Mr. Chairman, Ranking Member, and other distinguished members of the Subcommittee:

Thank you for this opportunity to testify. My name is Nancy Jensen. I am the author of the book, "The Girl Who Cried 'Wolf'", which chronicles my lived experiences as a person with a mental illness and a survivor of the horrific conditions of the Kaufman House in Newton Kansas. You've heard of the old TV show "Little House on the Prairie," right? Well the conditions in the Kaufman House were so terrible that it could be called the "Little House *OF HORRORS* on the Prairie."

The story the Kaufman House vividly shows why the Subcommittee must remove the parts of this bill which destroys the funding and effectiveness of both the Protection and Advocacy for Individuals with Mental Illness program (known as the "PAIMI" program) and the recovery programs (such as the Alternatives conference and others).

This bill pretty much destroys funding for the PAIMI program and takes away its ability to hold abusers accountable and protect the rights of people with mental illness, including the right to treatment. The PAIMI program helped finally shut down the Kaufman House, freed my friends, and helped us get justice. If this bill was the law only a few years ago, Arlan and Linda Kaufman would still be in the business today of terrorizing, abusing and enslaving people with mental illness. More people with mental illness would be suffering in terrible places like the Kaufman house.

I know how terrible the Kaufman House was. I was unfortunately a resident of that evil place. Arlan and Linda Kaufman ran an abusive group home in Newton, Kansas, for over 20 years. They called what they did "therapy." It was not therapy. It was cruel. It was horrible. It was sexual and emotional abuse. The Kaufmans forced their so-called patients to be nude, to do housework, and tend the farm in the nude. The Kaufmans forced residents to do bizarre sex acts while videotaping it. They billed Medicare for these so-called "therapy services." They treated us worse than dogs. I was forced to be naked, to sleep on the filthy floor, and to use a bucket for a toilet. I was degraded and told that I will never wed, never have a child, never join a church, and that I would never get a job. Well, as a proudly married mother with both faith in God and a job, I proved the Kaufmans wrong!

The PAIMI program shut down this house of horrors when no one else would or could. I was the first former resident to tell the State of Kansas about the evil happening there. Over a 20-year period, three more former residents and 11 Kansans joined me in telling Adult Protective Services (APS) and the State of Kansas about the Kaufman's reign of terror. APS and the State failed.

How did the PAIMI program get in and shut down the Kaufman House when the State could not? Three key reasons:

First, the federal PAIMI Act gives the Protection and Advocacy systems (called "P&As" for short) monitoring powers and independence to protect people's rights, including talking to the victim without others in the room, even in an unlicensed place like the Kaufman House and even when PAIMI does not have a client. Without a court order, APS was turned away.

Second, the PAIMI funding provided the P&A enough resources so that it could properly investigate the Kaufman House. PAIMI could then provide legal services to the victims for their rights and treatment as well as press for important and needed policy changes to stop future problems.

Third, and perhaps most importantly, with the PAIMI program the individual with a mental illness, the victim, is the client. The client is in charge. The victim decides what justice is. APS serves the interests of providers and the State.

As you can see in on page seven of my testimony, prosecutors praised the P&A and the PAIMI program for its ability to get into the Kaufman House when the State could not and to help ensure treatment for people with mental illness. For example, the Kansas Attorney General's office said at the time that the P&A through its PAIMI program "had the ability to go in and do some things under their authority that we [the state of Kansas] were not able to do…". Long story short, thanks to the PAIMI program working with prosecutors, the Kaufman House was shut down, people with mental illness obtained treatment, and Arlan and Linda Kaufman were found guilty on over 60 charges, including involuntary slavery. Thanks to the help of the PAIMI program, the Kaufmans are in prison today and I am here testifying. How cool is that?

This bill takes away the PAIMI program's ability to educate policymakers. The PAIMI program worked with me as a survivor to change laws to prevent future Kaufman houses. With PAIMI by our side we changed the law. Places like Kaufman House must now get licensed. Together with PAIMI we fixed guardianship laws. We started an Abuse and Neglect Unit. If this bill would have been the law, the PAIMI program could not have done all that, and similar situations would have continued to occur throughout the state. Systemic work protects people's rights and prevents abuse and neglect in an efficient and effective way.

Also, PAIMI does not just help victims of abuse and neglect. PAIMI protects the rights of people with mental illness. Because HR 3717 slashes funding for the PAIMI program it will make it harder people with mental illness to find housing, employment, and education. HR 3717 will prevent individuals with mental illness from receiving treatment. PAIMI serves people with disabilities in all these areas, not just preventing abuse and neglect. Since President Ronald Reagan signed the PAIMI program into law in 1986, it has been vital in securing appropriate treatment. This includes but is not limited to youth with severe mental health issues, adults with mental illness, as well as youth and adults with autism and other developmental disabilities who also have co-occurring mental health issues.

Another important lesson learned from the Kaufman House is the need to support recovery programs. Until I worked with PAIMI in 2006, I did not know that recovery was possible. Now I am an advocate for recovery. You need to have hope to recover. I fear this bill will take away the hope to recover by slashing funding to recovery programs.

I am also concerned that this bill would decrease the privacy protections of individuals with mental illness under HIPPA in order to provide families more access to information when it is not needed. Families of course are important to people with mental illness and their ability and opportunity to recover. Families already have access to a lot of information about their loved ones. The individual's right to privacy is what should be most important.

Finally, I believe that this bill has been misnamed "The Helping Families in Mental Health Crisis Act." I want to respectfully point out to the Subcommittee that the focus should be on helping individuals with mental illness in crisis and through recovery. While families are an important support, the focus must be on the person and their recovery.

Extended written testimony about HR 3717, more background on the Kaufman House case, the PAIMI program and Recovery Programs -

Who ran the Kaufman House?

The Kaufman House was owned and managed by husband and wife Arlan and Linda Kaufman. Arlan Kaufman was the so-called therapist, landlord, service provider, and guardian/conservator of one of the residents.

How the State of Kansas Served Its Own Interests, and Not the Interest of People with Mental Illness ... or how to make $75,000 while abusing people with mental illness:

The State of Kansas had investigated the Kaufmans several times. However, the State served its own interest, not the interests of the residents. The State would show up, knock at the door and get turned away because Mr. Kaufman was a guardian for at least one resident and the State wrongly assumed he was guardian for all of us. The State has an interest to have people with mental illness served somewhere. They do not always care where. The State of Kansas and its APS program did not want to go against that interest, even when former residents, like me, told them the truth. You have heard the phrase money speaks louder than words, right? Mr. Kaufman pushed back against the State of Kansas for looking into his group home. Mr. Kaufman sued the State. The State of Kansas paid Mr. Kaufman a settlement of over $75,000 to make this problem go away. That alone tells you all you need to know about the fact that the State serves its own interests. They paid off Mr. Kaufman to make him stop litigating in court. People with mental illness continued to suffer. Only the independent P&A and PAIMI program has the legal authority and funding to serve the interests of all the victims of abuse in a systemic way.

How did the P&A Help Prosecutors Find the Kaufman's Guilty? How did PAIMI help the victims? How did the case unfold?

The P&A got a report of the terrible abuse from former Kansas Attorney General, Phil Kline. General Kline was frustrated that the State agencies could not do anything. The deadline for the State to file charges had passed.

The US Attorney for Kansas, Eric Melgren, had originally turn down prosecuting the Kaufmans because he did not have enough evidence or a witness free from the

Kaufman's influence. The State of Kansas and Adult Protect Services (APS) was not able to help or obtain a resolution over a 20 year period. Unlike the State, the P&A represented us. The P&A believed us. They were OUR attorneys. The P&A used its "reasonable, unaccompanied access" under the PAIMI Act to do a full investigation. Because of this "reasonable, unaccompanied access" the P&A through its PAIMI program talked to a friend of mine, Barb, without the Kaufmans in the room. Barb told the P&A attorney "I don't want to be forced to be naked anymore. Please help me." The P&A attorney represented Barb and what she wanted. Not what the State wanted. The victims were now in charge.

The P&A got Barb out of that house of horrors. The P&A represented her in a court of law to get an emergency change of guardianship – Mr. Kaufman was also her guardian! The victims wanted to pursue criminal prosecution and restitution. As the attorney for the victims, that is exactly what the P&A did. The P&A provided information and a witness free from the Kaufman's influence to prosecutors. Prosecutors who had before would not press charges, finally had enough evidence to go forward. Thanks to the PAIMI program's "reasonable unaccompanied access," the P&A was able to ensure that justice prevailed. For 20 years, nothing happened. Six months after the P&A got involved, the P&A accompanied the FBI on a raid of the Kaufman house. The FBI seized over 30 videotapes from the Kaufman's bedroom, which vividly showed sexual abuse perpetrated on patients. The P&A was asked by the FBI and US Attorney's office to be on hand when the FBI executed its raid in order to ensure effective services and treatment for the residents of the Kaufman House. With the Kaufman's arrested and pending a trial, the P&A stepped in to ensure proper services and treatment for the now former residents of the Kaufman House.

The P&A and PAIMI program stepped in and protected the rights of the victims. The P&A obtained emergency change of guardianships for the rest of the residents. The P&A helped establish services and treatment for the residents. The P&A represented the victims civilly to ensure we were effective witnesses for the prosecution. The P&A represented the victims to obtain restitution. The Kaufman's were found guilty on over 60 federal charges, including involuntary slavery of people with mental illness and Medicare fraud. I am happy to report that Arlan and Linda Kaufman are in a federal prison as I speak here today. This group advocacy is an important and cost effective way to ensure positive changes for a large group of people.

What did Prosecutors say was Important about the P&A and its PAIMI program in Obtaining Justice for the Victims of the Kaufmans:

The main prosecutors of Arlan and Linda Kaufman were the US Attorney's office and the Kansas Attorney General's office. Below are quotes of what these Prosecutors had to say about the P&A and its PAIMI program. The direct quotes come from a documentary film about the P&A (called the Disability Rights Center of Kansas). It was the incredibly diligent and professional work of prosecutors along with the P&A through its PAIMI program that ensured a prosecution and enabled justice to prevail in this case.

The full documentary film on the Kaufman House can be found at:
www.drckansas.org/abuse

Loren Snell, Office of the Kansas Attorney General:
"DRC [as the P&A with its PAIMI program] had the ability to go in and do some things under their authority that we were not able to do or weren't able to do as quickly as they [the P&A] could get it done. They were able to step in and work on behalf of those individuals, the victims in that case a lot quicker than we could under the state system because they had other authority other regulations and rules that they could operate under that were going to allow them to do things and do them a lot quicker."

Eric Melgren, US Attorney for Kansas:
"One of the things that was unique about the Kaufman's approach was that we knew when we went in to execute search warrants and to make arrests of both Arlan and Linda Kaufman, that we were going to face the situation of having to have to have a plan in place to deal with the residents of the house. As I indicated, there were a number of adults who lived there who had various forms of mental illness or mental disabilities who either because they couldn't take care of themselves or had been conditioned to rely on others, weren't going to be in a situation to immediately provide for their own living and housing arrangements. Through the assistance both through referral to the Kanas Attorney General's office and to the assistance of the Disability Rights Center we managed to get court orders freeing the residents from those houses then we filed criminal charges both civil rights and health care fraud and abuse charges against both Arlan and Linda Kaufman."

Is this an Isolated Incident? Does Kansas differ in the way it conducts Adult Protective Services from Other States?

The Kaufman House is not an outlier. It is not an isolated incident. All across the nation, State Adult Protective Services and other State investigation programs are failing people with mental illness. Simply put, these investigative systems continue to represent the State's interests. The attorneys for APS represent and serve the needs of the State. The attorneys for the P&A represent and serve the legal needs to the person with a mental illness who is the abuse victim. The P&A can investigate and monitor facilities and where people with disabilities get services. The P&A can represent groups of individuals, instead of only one person at a time. H.R. 3717 would not allow this type of systemic advocacy.

The P&A and PAIMI Program Is the Premier System Fighting for the Rights of People with Mental Illness and Their Right To Receive Treatment:

Supporters of HR 3717 misconstrue what the PAIMI program does and how it helps obtain treatment for people with disabilities. I fear that some advocacy groups supporting HR 3717 are only focused on expanding institutionalization at any cost. The underlying bill will increase the need for expensive institutionalization. It redirects federal money away from innovative community based and recovery programs and towards involuntary commitment. Committing people with mental illness against their will is both expensive and ineffective. The focus needs to be on recovery, community-based services and protecting individual's rights. The PAIMI program helps people with mental illness, including those with the most serious mental health problems, obtain the treatment and support that they want as individuals. It protects our rights. Supporters of HR 3717 apparently do not like the PAIMI program and the systems change it performs. Well, they have not walked a mile in my shoes. I have seen first-hand how the PAIMI program and the P&A works with individuals with mental illness, to be their advocate, and to help pass laws enhancing our rights and increasing access to treatment, services and supports.

PAIMI helps people with mental illness all over the nation. The National Disability Rights Network can provide this committee numerous examples of how PAIMI helps people through both individual advocacy and systemic work. For example, the Arizona Center for Disability Law (who has the PAIMI program) reached a settlement to help increase services for people with seriously mental illness in Arizona. Thanks to this settlement, services including everything from medications to housing and supportive employment will now be more readily available to these individuals with mental illness. Governor Brewer credited the mental health advocates, including the P&A, with providing "the hammer" to ensure the state lives up to its legal obligations.

PAIMI Program Helps Millions of Americans:

The Kaufman House case is just one example of the work occurring every day across the country by the nationwide network of P&A agencies implementing the PAIMI program. Last year alone, over 15,000 individual cases, over 35,000 Information and Referrals, over 80,000 stakeholders were trained on rights and other topics, along with over 39 million people positively impacted through systemic advocacy by the PAIMI program. Think of the millions of people, families and society as a whole that have been positively impacted by the PAIMI program since it started in 1986.

HR 3717 harms the Mental Health Block Grant and Pushes Involuntary Outpatient Commitment:

This bill places negative strings on the federal mental health block grant money, hurting innovative programs and pushing involuntary outpatient commitment. This is bad policy. As I understand it, this bill would stop states from receiving federal mental health block grant funds (used to support innovative, evidenced-based services) unless they are forcing involuntary, court-ordered outpatient commitment. This is both ineffective and costly. It is also not based on the recovery model. It infringes on the independence and choice of Americans with mental illness. It would also have the effect of reducing funding for important and innovative community-based services in favor of involuntary treatment.

Mr. PITTS. The Chair thanks the gentlelady and now recognizes Ms. Zdanowicz for 5 minutes for an opening statement.

STATEMENT OF MARY ZDANOWICZ

Ms. ZDANOWICZ. Thank you, Mr. Chairman, members of the subcommittee.

I have been involved in advocacy for people with severe mental illnesses and their families for many years, and I really have no hope that some of the things that have created barriers to treatment would be addressed until Congressman Murphy introduced the Helping Families in Mental Health Crisis Act.

I too want to talk about the protection and advocacy program, and while I think the original intent of the program and the original practice of the program was very important, it has lost its way, and I will share a personal experience that is very difficult to talk about. My sister has schizophrenia. She has been ill since she was 18 years old. She has spent most of her adult life in state psychiatric hospitals. For the most part she has received good medical care and they have protected my sister, who is very vulnerable. But in 1998, the State hospital that she was in closed. She was moved to a hospital that had less than 500 patients, but because of the loss of beds due to the hospital closure, the patient population grew from 500 to 750 patients by 2007. I knew what was happening at the hospital to some extent, and I was able to get her moved to a facility that was safe, but a few years later I was able to get her medical records, and I found out what was really happening and just how bad things were, and I am still haunted to this day by what happened to patients that didn't have a family to protect them, and the protection and advocacy organization was nowhere to be found.

The problem is that the bill that created protection and advocacy was enacted in 1986. The first finding in that bill is that patients or persons with mental illness are vulnerable to abuse and serious injury, and so it created a federally funded organization independent of States to monitor care of patients in hospitals and facilities. Now, at that time there were 250,000 people in State psychiatric hospitals. Now there are fewer than 35,000, and the protection and advocacy organizations have changed course as a result, and not necessarily in a good way.

I will give you an example from Massachusetts, which is the State where I live. That organization reported spending more than $250,000 on lobbying, federal funding on lobbying against State measures, and more than $100,000 actually went to professional lobbyists, but it isn't just lobbying that is the problem. In Massachusetts, that organization got government funding to conduct a study of community services, which to me is very important because I have a brother with schizophrenia who lives in a group home and I am his guardian, and I work very closely with staff and the management of that group home to make sure he is safe in the community. But I was appalled when I read the report, and one of the findings was that guardians should not be involved in protective measures that should be used for individuals living in the community, and a finding that GPS devices that are used for people who have a history of wandering and getting injured are a violation of individual rights. It is just a perversion. If you look and compare with the Alzheimer's Association view on that, they find it an appropriate use of electronic devices to have a comprehensive safety program for people who need it and may be unsafe in the community.

So I want to say that Congressman Murphy's bill really will do what it is named, and that is, it will help families who are in mental illness crisis.

Thank you.

[The prepared statement of Ms. Zdanowicz follows:]

Testimony of Mary Zdanowicz

Since the early 1990s I have been an advocate for the most severely mentally ill and their families who face countless barriers when trying to get treatment for a loved one. Many obstacles are due to federal policies that do more harm than good. There was little hope that Congress would remedy these problems until Congressman Tim Murphy (PA) introduced the *Helping Families in Mental Health Crisis Act* (H.R. 3717) in December 2013.

There are myriad examples of federal funding gone wrong. I come from the Commonwealth of Massachusetts, home of the beloved Senator Edward Kennedy. Among his most important legislative achievements was the *Protection and Advocacy for Mentally Ill Individuals Act of 1986* ("PAIMI"*)*. The first Congressional finding cited in PAIMI was that "individuals with mental illness are vulnerable to abuse and serious injury." At the time, there were more than 250,000 psychiatric beds in the country, but states were not equipped to monitor the care of so many patients. The Senator planned a federally funded system, independent from states, for monitoring and protecting the rights of the mentally ill. Now, nearly thirty years later, fewer than 35,000 state psychiatric beds remain. As a result, non-profit organizations created under PAIMII, such as the Disability Law Center, Inc. ("DLC") in Massachusetts, have changed their focus, but not always in a good way. It is doubtful that Senator Kennedy would have sanctioned the use of federal funds for lobbying against state legislation. Between 2010 and 2013, DLC reported spending $267,388 for lobbying; over $100,000 was paid to professional lobbyists.

I was the Executive Director of the Treatment Advocacy Center (TAC) for many years. TAC's mission is to eliminate barriers to treatment for individuals with the most severe mental illnesses and pursues its mission without any governmental funding. TAC supports legislation for assisted outpatient treatment (AOT), which is a form of court ordered treatment for individuals who need medication to survive safely in the community, but who may be unaware of their illness due to a neurological disorder called anosognosia. PAIMI organizations (such as Protection & Advocacy or Disability Law Centers) used federal funding to lobby against AOT legislation in New Jersey, Pennsylvania, New Mexico, Florida, Maine, and many others.

It is more common to find PAIMII organizations lobbying in the halls of state capitols than monitoring for abuse in psychiatric hospital wards. I have personal experience to share as an illustration, although it is difficult. My sister has severe schizophrenia and has been in state psychiatric hospitals for most of her adult life. Most facilities have provided quality medical care and protection for my vulnerable sister. But in 1998 she was moved from New Jersey's largest hospital when it closed to a smaller state hospital with less than 500 patients. Due to a shortage of beds, the census in the hospital reached 758 patients by 2007. Hospital staff were overwhelmed and the overcrowding made it a dangerous place. I knew some of what was going on and managed to have my sister moved to a safer hospital. The extent of the abuse became apparent when I later obtained my sister's records. (Exhibit A). I am still haunted by the patients who had nobody to protect them. Where was the federally funded PAIMI organization? They were in Trenton lobbying against New Jersey's AOT bill, a bill that ultimately passed.

Most PAIMII organizations appear to be unable to strike a balance between an individual's right to liberty and society's obligation to protect its vulnerable citizens from harm. For example, the Massachusetts DLC conducted a study of community services ranging from hospital discharge planning to housing programs for people with mental illness. The report asserted that a guardian for person incapacitated by mental illness should not be involved in decisions about whether protective measures should be employed in the individual's community residential living. One situation that DLC reported as a violation of individual rights concerned a resident who was "wearing a GPS device because he has a history of wandering and getting hurt." Compare that with the Alzheimer's Association position that "the use of electronic tracking devices and related technology may be an appropriate part of a comprehensive safety plan."

Section 1141 of H.R. 3717 would place sensible restrictions on PAIMI grantees so they could no longer use taxpayer dollars to lobby. PAIMI programs would return to their roots of investigating cases of abuse and neglect against a very vulnerable population.

Redefining PAIMI's mission and reducing funding will remove the impediment so that states can provide quality care to the most severely ill. Congressman Murphy's bill will begin the necessary steps to rein in an out-of control agency in SAMHSA to focus its resources on caring for the most seriously mentally ill to. The reform of the Institution for Mental Disease Exclusion (IMD), which prevents states from receiving Medicaid reimbursement for psychiatric patients in state and private facilities, will slow the closure of state psychiatric hospital beds. The SAMHSA and CMHS reforms, such as linking the $450 million mental health block grant to requiring states to adopt need-for-treatment standards and assisted outpatient treatment, will reintroduce the notion that severe mental illnesses exist and until they are cured, barriers to treatment must be eliminated.

Mary T Zdanowicz is an attorney in Eastham, MA and specializes in mental health law. She is the former executive director of the Treatment Advocacy Center in Arlington, VA and is guardian for two siblings who have schizophrenia.

Mr. PITTS. The Chair thanks the gentlelady, and notes that Dr. Welner still has not been able to get here. If he comes in during the panel, we will permit him to give his testimony at that time, but I will begin the questioning now and recognize myself for 5 minutes for that purpose.

[The prepared statement of Mr. Welner follows:]

Chairman Pitts and Ranking Member Pallone,

Thank you for inviting me to speak to you today. My name is Dr. Michael Welner. I am a psychiatrist and forensic psychiatrist. I come to you to encourage you to vote to pass HR 3717 to a vote for the full house.
HR 3717 t is important to you as your own constituents, as fathers, mothers, and grandmothers who may one day interact with a person like myself for reasons that are your worst nightmare, worse than something concrete like heart disease, who might one day confront the inscrutability of your own mental infirmity at the boundaries of the skills available to you, who might have a son like Representative Creigh Deeds whom you cannot save, who might be the only support for an autistic child, who might be at the boundaries of a loved one who refuses help, where medication no longer helps, or where the therapy advances are 300 miles away.

I was originally asked by the Energy and Commerce Subcommittee on Oversight and Investigations to participate in a mental health reform panel convened last March on lessons from Newtown in my capacity as Chairman of The Forensic Panel. In my practice, we scrutinize the criminal who survived his shooting rampage, the hospital being sued for negligence for discharging someone who commits suicide, the mother who kills her five children days after her medication dose is lowered, the head injured Iraq veteran who blows up his commanding officer, the sex offender who everyone knows will offend and does. We see the messes of bigger problems from all over the U.S. before they become discussions in Congress.

I have studied Helping Families in Mental Health Crisis Act with this inspiration in mind:

What is the nature of a mental health **crisis**, and what are the consequences of that **crisis**?
Who is in a mental health crisis?
When is there a particular risk of crisis?
Why is a particular crisis happening more frequently than it should?
How is a particular crisis to be solved?

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What is the nature of a mental health crisis, and what are the consequences of that crisis??

Contemplated violence. Unfettered impulsivity. Destructive command hallucinations. Suicidal urges. Explosive abuse. Descending chemical dependency. Neglect of the vulnerable child.

Every crisis is different and requires proactive intervention to prevent tragedy. This is what distinguishes crisis in any aspect of medicine and in society.

Wherein the law would currently define a mental health crisis as **danger to self or others**, that word *danger* bedevils the decision maker and damns the family in the mental health crisis. If it's your family, and someone is considering violence on their own timetable, the law says it's currently not immediate enough to intervene. I've examined six mass killers; when they decide they are going to be dangerous, it's too late for you to stop them because they will make sure the doctors never know.

If it's your family, and your sister is a battered woman, you know that Impulsivity and explosive abuse doesn't have to happen every day or every month.

If it's your family, you aren't hearing what the voices say, and if you are hearing voices, chances are they relate to your family. What then, if they are your frightening and irrational secrets?

Suicidal urges may come and go, or come and come. Now, what if you are the child of a suicidal parent? Or spouse and fellow parent?

In any one of the above, something may be happening that creates neglect of the vulnerable child. Long before I examined Andrea Yates, she knew she was neglecting her children and then killed them as a solution to her own incompetence. While she was receiving exemplary mental health care. And no one speaks for the children.

The Helping Families in Mental Health Crisis Act embeds the notion of danger in the real world of **what is a crisis**. Not "danger to self or others," or "imminent danger" which right now is a barrier getting in the way of admission, program eligibility, continued care, and access to services. Rather, HR 3717 focuses on directing services to crisis situations designated as "may be dangerous to self or others, unwilling to undergo treatment, may be unable to provide for basic needs, including safety, or a condition which if not timely treated, is likely to substantially deteriorate," which invariably bear consequences and risk to those who are in crisis and to their families.

This is wording that is meant to prevent cracks from allowing even the best of intentions to miss the person who is in crisis from crawling in. This extremely important change is not meant to encroach on personal liberties and doctors and families are not inclined to do that anyway because whenever you bring care or commitment to someone who is mentally suffering, you are on the front line and it is you who get their anger, abuse, and venom. Those who care are willing to endure that. But right now the law does not allow caregivers to get help for people in crisis.

Who is in mental health crisis?

It is that person in the above mental health crisis who denies there is a problem. And the family cannot get through that denial.

It is that mental health crisis involving a person who does not fall in the cracks, but crawls into the cracks because the person does not want treatment, from any mental health professional

It is that person whose coping qualities are so immature that decisions coming are doomed to create risk to self or to others

It is that person who feels isolated in their hopelessness, because their issues go beyond a chemical imbalance

It is that person who is hopeless and desperate, diagnosis or not.

The Helping Families in Mental Health Crisis Act:

- Funds the expansion of Assisted Outpatient Treatment. In so doing, HR 3717 enables treatment to reach those in crisis and to whom it must but otherwise would not
- Funds expansion of cooperative efforts with law enforcement to recognize mental health crisis and to enhance crisis intervention
- Develops cooperative efforts with corrections settings to provide mental health services to inmates whose crisis leads to incarceration and elevates risk for continued reoffending and victimization of others

When is there a particular risk of crisis?

It may be hard to tell. No one knows the person in crisis like responsible and close caregivers and family. A doctor sees a person, if at all, for only an appointment. And the seriousness of a situation can be overlooked by a doctor when the person in crisis is in denial or is misleading the impression of the doctor or therapist.

HIPPAA laws currently are used as barriers preventing doctors and caregivers from getting information from (and even to) caregivers at critical times; and, from involving families in crisis treatment planning. Educating health care providers about what allowances HIPAA now gives for disclosure would not solve the problem; it is easier for doctors not to breach their privacy with their patient, and so they do not. A patient can easily assure a doctor that no imminent risk to any identifiable person is present in order to keep caregivers from exposing high risk activity.

The Helping Families in Mental Health Crisis Act facilitates communications between families and caregivers during time of crisis, "in order to protect the health, safety, and welfare of one or more individuals." A broader definition of public safety gives doctors more of a stake in protecting others from a patient at risk, and enables caregivers to have necessary access in times of crisis.

Why is a particular crisis happening more frequently than it should?

Mental health is no different from other medical specialties – an exploding knowledge base creates important subspecialty niches to better focus care. What one trains in to master child psychiatry is very different from what one needs to master for substance abuse psychiatry, which is far different from what one would need to know for crisis intervention, or psychotherapy with the chronically suicidal. There are many areas of the country with few subspecialty-trained mental health professionals to meet the population needs. Community mental health centers are sorely understaffed with those with subspecialty expertise.

Knowledge of the brain and subspecialty research discoveries have matured the behavioral sciences. Yet unlike any other medical specialty, the administration of mental health resources is heavily influenced by substance abuse treatment models that are often antagonistic to medication compliance and psychiatrists as external influences on patient care. Would the national health system have holistic medicine control the budget for medicine and surgery? Of course not. Would any other specialty submit to having its budgeting controlled by leadership that ideologically rejects medical intervention and embodies denial of illness?

Think about it. Let's say such a movement existed to stop taking anticholesterol medicines as harmful, opting for control of the food supply to eliminate certain aspects of the foodstuff. Noble goals, perhaps, but would we have such an organization with such goals administer the budget for medical care and research and hospital medicine? Would you in Congress allow for physical therapist organizations to control the budget allocations for surgery disciplines? Of course not. The behavioral sciences and its administration cannot be a subspecialty working at cross purposes with itself. So, why are the resources for mental health so controlled by forces whose ideology is overtly antagonistic to staples of psychiatric treatment?

Reimbursement remains disproportionately poor to medication treatment. As a result, psychotherapy, which may be the best treatment option in a given crisis, withers and cannot be found when needed.

The sickest patients may need the most services. Yet those who make themselves available for the hardest to treat and those most likely in crisis are reimbursed the least.

Closing of hospitals and reducing beds is a direct byproduct of mistaken short-shrifting of the acutely ill and at risk.

In order to make the treatment of those in crisis, be they children, the repeatedly violent, those with stubborn drug addiction, those post-incarceration or with compliance problems, we need to make crisis psychiatry a growth industry. The hardest patients deserve the best and brightest.

Liability risks deter psychiatrists from crisis patients just as obstetricians shuttered their high risk practices and neurosurgeons did theirs. Honesty about what crisis is – and what it entails – demonstrates why litigation risk drives the best and brightest away from a calling to help those in need. Risk is native to crisis management. I know, I started my career treating the repeatedly violent. I know what it's like to have a patient attack his dad in front of me at 10 PM in response to hallucinations – with no security down the hall for me to call. I also know what it's like to have a patient who tells me he has killed before to test the therapy. So why aren't those who have the courage to manage those in crisis protected like emergency responders and police officers?

The Helping Families in Mental Health Crisis Act:

- Ensures that mental health funds are allocated to those programs promoting mental health care and compliance with care, not experimental models rejecting treatment and promoting denial of illness.
- Fulfilling staffing needs for the necessary range of subspecialty expertise to otherwise underserved areas for both medication and psychotherapy expertise, specifically child and adolescent psychiatry, crisis prevention, treatment of violence, dual diagnosis issues
- Ensures access to vital medications by codifying a requirement that Medicare and Medicaid offer all, or substantially all, antidepressants and antipsychotic medications
- Providing a range of crisis management and stabilization services to underserved areas
- Explores changes in reimbursement to promote treatment of the underserved and those in crisis and those needing more services, and incentives for demonstrated quality of care
- Promotes liability protection for those giving of themselves to underserved areas

How is a particular crisis to be solved?

Mental health resources need to be dedicated to a mission that respects all aspects of treatment, including medication, psychotherapy, and hospitalization, as essentials of mental health crisis management.

Collaborative mental health care models must be implemented so psychiatry can be complemented by crisis intervention skills and resources of law enforcement, corrections, schools, and houses of worship – each available to engage families in crisis.

Promote psychiatry as a science and public resource. If psychiatry is stigmatized, its patients are stigmatized. If we want to diminish denial of illness, we need to destigmatize psychiatry as a diagnostic and treatment source. It is no different from public service. When the dignity of public service is debased, those served no longer respect the institutions.

Do not let the illness drive the treatment. Denial is not to be confused with determination to overcome. Denial has no place in medicine. Denial has no role in crisis management.

The Helping Families in Mental Health Crisis Act of 2013:

- Consolidates resources in a structure of a National Mental Health Policy Laboratory, whose mission requires the seamless integration of biological and psychotherapeutic treatments to promote established treatments for mental illness and substance abuse, reduce mortality, and advance rehabilitation
- Identifies and pursues research initiatives with the above scientific inspiration in mind and integrating the National Institute of Mental Health, the justice system, corrections, and law enforcement in policy planning with mental health consumers and families, and end user practitioners
- Promotes education about the potentials and progress of mental health care

- Operationalizes multidisciplinary models for mental health intervention in underserved environments, linking mental health centers, families, psychosocial supports, the justice system, religious organizations, and law enforcement
- Promotes mental health assessment and response training of corrections, law enforcement professionals and first responders

I have treated patients for twenty years, and have been board certified in forensic psychiatry, psychiatry, disaster medicine, and psychopharmacology. The latter is notable here. Congressman Murphy is a psychologist. I am proud of the medications I prescribe, proudest when I tell a patient I am discontinuing your medicine because you don't need it or me. I also recognize the psychotherapists, social workers, and counselors who make a difference when medicines are not the answer or not the full answer.

And I too am a psychiatry constituent. I tried in vain to commit my psychotic sister who had no lesser right to a great life than I have, but she was one of those people who, no matter what she did, was never a danger to herself or others. She ultimately became the woman I buried at age 32. My last letter from her before she disappeared, only to be found six months later, was to thank me for how I spoke about her when I had her committed. I learned as you indeed will that when the illness runs the care and the situation, the care is psychotic and may be suicidal as well. No matter who you are or who you know.

I am the responsible provider for another family member with serious mental illness. He is adamant that there is nothing wrong. He is dependent upon me financially – flexibly accommodated at our office, in fact, in exchange for agreeing to take his antipsychotic, going to the gym, staying on the diet his naturopath made for him and practicing guitar. He would crawl into the cracks otherwise. In therapy, he runs the message. And when he falls apart because he cannot tolerate certain stresses of interpreting the rational world, his therapist does not allow for a line of communication. When things go wrong, I'm the first to see and the last to know what is happening. He is the first to know what is happening and the last to say anything or to know what to do, but I am expected to pick up the pieces when he falls and to protect him. I'm all he's got. And like many parents, grandparents, and other relatives in the same position, I likely care more about his rights than he does.

My heart breaks for him. He is highly educated and sweet and gentle. He never did anything to invite the onset of his condition. I wish I could take away his illness. But denying his illness does me no more good than were I to deny lupus or any condition one is better off living with by treating with psychiatry as a partner.

I will not bury another. Nor should any of those families whose loved ones' autopsy reports follow me every day as a forensic psychiatrist. We are here not because of their loss, but because the Lanza tragedy demonstrated how crisis does not always stay in the family.

Our imperative is Helping Families in Mental Health Crisis. Thank you and may God bless you to take up the people's business with the decisiveness with which crisis management must transcend self-interest that would sacrifice the national good. And may God bless you with a mental health system that you have built to respond when crisis finds you as well.

Mr. PITTS. Ms. Thompson, in your experience, has the HIPAA privacy rule been misapplied to the effect that it serves as a barrier for helping the very people responsible for providing care in the community?

Ms. THOMPSON. Absolutely.

Mr. PITTS. Could you expound on that?

Ms. THOMPSON. What my experience was with HIPAA was that my family was consistently kept separate from my mother's medical needs, health care needs, psychiatric needs. We were unable to talk to physicians until we got guardianship at the end, which we weren't able to get guardianship until the last 9 months of her life because of the difficulty in gaining access to physicians telling us what was going on. As a professional advocate, I learned how to communicate with doctors. Most family members don't have that knowledge. I was fortunate enough to have gone through the training and professional experience to be able to tell a doctor he doesn't have to say anything to me but he has to listen to me. Most family members don't know that that is their right to say something. And so there is a lack of education on both sides, and the continued hiding behind HIPAA has got to stop.

Mr. PITTS. Ms. Zdanowicz, in your opinion, how has the legacy of deinstitutionalization of the mentally ill worked out over the past half century?

Ms. ZDANOWICZ. Well, this is one of my most passionate issues because I have seen the effect of closure of state psychiatric hospitals, and that is why I think the IMD exclusion is so important. I view it as discriminatory provision because it is the only population that is precluded from Medicaid coverage in hospitals.

A perfect example is when the hospital is closed where my sister was and she was moved to the other hospital, and there were not enough hospital beds left, which created this overcrowding, which just prevented people from getting treatment. Now, on the other hand, I do want to recognize, Congressman Pallone, Congressman Lance, that New Jersey has what is a gem in terms of psychiatric hospital treatment, and that is the Greystone Psychiatric Hospital, and that is where my sister is now and she is receiving just superior treatment. So it can be done correctly. But if you continue to close hospitals, there won't be enough beds, and people will end up where they are now: in jails and prisons. I just finished a survey of all the jails and prisons across the country, and I can tell you, they are the new psychiatric hospitals.

Mr. PITTS. Ms. Thompson, back to you. If you could choose one thing that the government could have done to help your family, what would it be?

Ms. THOMPSON. Just one?

Mr. PITTS. Well, you can name more than one.

Ms. THOMPSON. It would be that my mother was protected from herself. I come at this from so many different angles. I understand patients' rights. I wholeheartedly believe in them. I help fight for them. But when someone lacks the capacity, there is no shame in lacking capacity. When someone lacks the capacity, we need to take care of them, and that did not happen with my mother. She fell through the cracks over and over and over again, and if there had been more support for her, there would have been ongoing treatment for her. When my mother went through treatment, she would come back and everything would go back the way it was because there was no follow-up. She came home, and we didn't have the ability to do what we do.

I see it with families now. A family member, a son or daughter is hospitalized for a 72-hour hold and gets discharged home and the parents don't know how to create the right environment to keep that person on the road to recovery. They don't have the skills. There needs to be ongoing support. There needs to be more IMD beds. There needs to be this ongoing system of support for family members and for the person with the diagnosis.

Mr. PITTS. My time is expired. The Chair recognizes the ranking member, Mr. Pallone, 5 minutes for questions.

Mr. PALLONE. Thank you, Mr. Chairman. I am trying to get two topics in with Dr. Shern, so if I cut you off a little bit, it is because I am trying to get to the second set of questions.

The first relate to ACA and compliance with parity laws. As I said, Mr. Chairman, I am pleased we are having this hearing but I am troubled by a number of provisions in this bill, but it is a wide-ranging effort to address some important issues.

I wanted to discuss again the Affordable Care Act and the Mental Health Parity and Addiction Equity Act. The Mental Health Parity can enshrine in law the principle that mental health care is just as important as physical health care, and then the Affordable Care Act not only extended this principal to the individual health insurance market but also required that all expanded Medicaid programs as well as individual and small group health insurance plans cover mental health and substance abuse services as part of the essential benefits package. I hope my Republican colleagues understand that they are voting to repeal these advancements for mental health when they support the Ryan budget or vote to repeal the ACA.

So questions. Dr. Shern, what is your view of the importance of health insurance coverage and mental health parity and expanding access to treatment and improving health?

Mr. SHERN. It is absolutely critically important. Because of the development of the mental health treatment system in the United States, we have systematically discriminated against individuals with mental illnesses. That was largely repaired with the parity bill and further extended into markets that the parity bill didn't apply to by its unanimous incorporation into the Affordable Care Act. Getting to people sooner with effective care is critically important in terms of trying to stem these problems. Insurance access is a major impediment for individuals with mental health and addiction conditions is critically important.

Mr. PALLONE. And then secondly, these laws were clearly major steps forward but effective implementation and enforcement are essential. What more can Congress do to ensure health insurers are fully complying with the letter and the spirit of both the ACA and the parity law?

Mr. SHERN. I think that this House bill that is under consideration provides an excellent opportunity to provide resources to the Department of Labor and to the Department of Health and Human Services to assess the degree to which the parity bill is being effectively implemented across the United States and to provide ongoing guidance to insurers and payers and primary consumers about what they should expect to be their rights under this bill and the appropriate boundaries with regard to insurance coverage. So it is a complex bill. Equity in coverage is not something that is easily determinable. It has a large State influence, so I think it is very important that we systematically monitor it, and that would be a very helpful addition to this legislation.

Mr. PALLONE. All right. Thank you. Now, I want to get to this Wall Street Journal editorial, which I think the chairman introduced into the record. They ran an editorial that sharply criticized SAMHSA's effort to provide services that help individuals prevent, treat, and recover from mental health disorders, and they called SAMHSA the vanguard of the legacy advocacy and anti-psychiatry movement, accused the agency of wasting taxpayer dollars on programs that do not help those with the most serious mental illnesses. Obviously these are very serious allegations. How would you respond to this editorial's characterization of SAMHSA?

Mr. SHERN. It is, from my perspective, almost entirely inaccurate. If you look at the major—we talked about the deinstitutionalization and the problems with deinstitutionalization, and that surely was a policy that was well intended but very poorly implemented. If you look at every major reform since deinstitutionalization in terms of improving services for people with mental illnesses, many of the things we talked to you about today, SAMHSA has been the champion of the reform. They started the Community Support program, which is the first effort to try to build an adequate community treatment system for people with severe mental illnesses. They started the Child and Adolescent Support program. With Congress's support, they implemented the Assistance with Care Act. They have implemented acts around people with dual disorders. We could go on and on and on.

I think one of the things that is unfair is this characterization of SAMHSA as an entity that is anti-psychiatry, anti-treatment, anti-medication. That is just not true.

Mr. PALLONE. The editorial also claims that very few of SAMHSA's evidence-based programs focus on individuals with serious mental illnesses. Can you comment on SAMHSA's work in that area?

Mr. SHERN. Our estimate is that over 80 percent of—no one remembers that SAMHSA is an agency that addresses both mental health and substance use issues. If you look at the mental health portion, our estimate is about 80 percent to 85 percent of their resources are spent on issues related to and persons who have severe mental illnesses. So again, I just feel this is a gross mischaracterization of the SAMHSA program.

Mr. PALLONE. Thank you.

Mr. PITTS. The Chair thanks the gentleman and now recognizes the vice chairman of the full committee, Ms. Blackburn, for 5 minutes for questions.

Mrs. BLACKBURN. Thank you, Mr. Chairman. I thank each of you who are witnesses for being here and for adding to the work that we have done. I do want to thank Dr. Murphy for the work he has done with our committee. I think that because of the work he has done and concerns that we are hearing from our constituents, especially now that we are highlighting this issue, we have learned about the size and the scope of untreated mental illness and exactly where it affects families and individuals.

We have also, and Ms. Thompson, this speaks to some of yours, we have talked about the privacy laws and the impact that that has on public safety and also looked at federal resources and how those are utilized, and you are certainly adding to that discussion today and we appreciate it, and we are pleased with the components that the new legislation would put in place, some redirection, some refocusing, and we think that those are good and they are appropriate.

I do have a couple of questions that I wanted to ask, and I will be brief on these.

Ms. Thompson, I did want to come to you first. I want to thank you for sharing your story. As we looked at HIPAA and FERPA and the privacy issues. What I would like to hear from you, as we look at reforms, through what you have experienced firsthand and what you have learned through your caregiving and your advocacy, give me maybe the top three or four things that you would say this is what you need to change as you look at HIPAA and FERPA reforms. Do you have that laundry list? Could you give that to us?

Ms. THOMPSON. I don't know if I have a laundry list but I can tell you that I think what is important is that when somebody is—if somebody—I work with the developmentally disabled population as well. It is automatic. They have a condition before the age of 18, so there is no HIPAA violation. The parents are clearly the guardian. They become the guardian. They go through what is legally necessary.

Mrs. BLACKBURN. Been through the qualification?

Ms. THOMPSON. Correct. What happens with mental illness is that oftentimes that doesn't present until after the child is no longer a child, so at that point you are trying to shut the barn door after the horse has left, if you will forgive the analogy. There need to be some qualifications in place with HIPAA that make it clear when somebody is not able to make decisions when there is a question as to their safety or the safety of others, that relinquishes professionals, that doesn't allow them to keep their hands tied.

Mrs. BLACKBURN. OK. So almost like a revisit of a power of attorney?

Ms. THOMPSON. Yes. Right now you can try to get the individual to sign off but if somebody doesn't think they are ill, they are not going to sign off permission. That doesn't mean they are not ill and not in need of help.

Mrs. BLACKBURN. So you would encourage us to have some type of allowance or avenue that that oversight you could negotiate?

Ms. THOMPSON. Like a waiver, and maybe that—I don't know. As I said before, I am not a legislator. I don't know. Maybe having—if the physician deems it necessary or maybe getting two physicians to deem it necessary that HIPAA can be broken in this instance. It can't just be because somebody is going to commit a crime or they are going to kill themselves. They need to get help before that.

Mrs. BLACKBURN. OK. Ms. Zdanowicz, I can tell you want to weigh in on this. I see you nodding your head.

Ms. ZDANOWICZ. I have to agree completely. I actually would say the same thing. I was unable to get information about treatment for my brother and sister until I got guardianship, and I paid $5,000 to get guardianship for my sister, who was in agreement. She did not object to it. But I had that in order to get information, but even with that, for example, when I know my brother is in a hospital, a particular hospital, I have been told he was transferred there, and I call and they say we can't tell you if he's here, and then I will fax my guardianship papers and they'll still say HIPAA prevents us from talking with you, and then I learn later that they have changed his medication in a way that I already know is not helpful and there is nothing I can do about it, it is too late.

People don't understand HIPAA, and I often tell families, if you are told that they cannot tell you anything about your family member, you are still free to tell them what they need to know about your family member. It is a terrible obstacle for families to help, and I totally support the revisions to that portion of the bill.

Mrs. BLACKBURN. Thank you. Yield back.

Mr. PITTS. The Chair thanks the gentlelady and now recognizes the ranking member of the full committee, Mr. Waxman, 5 minutes for questions.

Mr. WAXMAN. Thank you, Mr. Chairman. I want to apologize to the panel because there is another subcommittee meeting at the same time, and I have been required to go back and forth.

Ms. Jensen, I want to start by thanking you for being here today and telling us your story. It is a deeply personal one, and I was struck by the utter failure and inability of authorities in your State to bring an end to the terrible abuses of people with mental illness, including yourself, at the Kaufman House, that is, until the P&A became involved. Can you elaborate on whether or not Kansas was an outlier and not adequately addressing complaints about the Kaufman House prior to the P&A's involvement? Do you think it is unique?

Ms. JENSEN. All I can say is that there were 12 complaints to the Adult Protective Services, and he even sued Adult Protective Services, and so they quit coming to the door. And so I believe that I know for a fact if it wasn't for PAIMI, Kaufman House would still be going on.

Mr. WAXMAN. We have heard from witnesses today that P&As lobby, and in fact, in the testimony, you worked with the P&A to change laws that would prevent future Kaufman Houses through licensure requirements, guardianship laws and the establishment of an abuse and neglect unit. Can you clarify whether the federal funding was used for these activities and any other lobbying activities? Do you know?

Ms. JENSEN. No, there was no federal funding. I and my friend, we just never wanted it to happen again, so we were volunteers. We did it ourselves, and it was educating us on the issue but there was no financial spending of federal funds to get these laws passed.

Mr. WAXMAN. Proponents of the PAIMI proposals in H.R. 3717 claim these provisions will return the program to its roots but it seems to me that an 85 percent reduction in federal funding would do much more than that. How would a funding reduction of this magnitude impact the ability of the P&A in Kansas and P&As around the country to protect the rights of people with mental illness?

Ms. JENSEN. I am so scared that if you take PAIMI away, and that is what would happen, there wouldn't be any protection for us if we were being abused, neglected or exploited. There wouldn't be anyone coming in and taking us out of that situation in order to talk to us and investigate the situation, and I just ask you not to do that.

Mr. WAXMAN. Well, your testimony is very persuasive and I think quite valuable to us to hear that point of view.

I want to ask Ms. Thompson and Dr. Shern, I am pleased that my colleagues and I have some points of bipartisan agreement on issues before us. We all believe that mental health care is an essential part of our health care system. We agree that we need to work to end the stigma that surrounds seeking treatment, and we agree that we need to invest in community-based approaches for care so that individuals who need help are able to get it. I think everybody here on the panel would agree with these goals as well. But I also believe that witnesses invited by both Republicans and Democrats today agree that expanding access to health insurance and improving health coverage of mental health services are critical.

Ms. Thompson, as a general matter, do you think individuals who have health insurance have a better chance of getting into treatment for their mental health conditions?

Ms. THOMPSON. I am sorry. Can you——

Mr. WAXMAN. If you have health insurance, don't you have——

Ms. THOMPSON. Oh, absolutely.

Ms. WAXMAN. And do you think including mental health coverage as an essential health benefit and requiring it be covered at parity with physical health were important steps forward?

Ms. THOMPSON. Yes.

Mr. WAXMAN. And Dr. Shern, do you agree with that?

Mr. SHERN. Absolutely.

Mr. WAXMAN. I think, Mr. Chairman, we could learn a lot from these witnesses. There is a lot more to the ACA than we can fit into 30-second attack ads. But it advances a number of essential priorities that both sides agree on, and I hope we can agree that it is here to stay, that we should build off of these things that we agree on in the law rather than constantly focus on repealing or undermining it.

I see my time is over and I will yield back the balance.

Mr. PITTS. The Chair thanks the gentleman and now recognizes the vice chairman of the subcommittee, Dr. Burgess, 5 minutes for questions.

Ms. ZDANOWICZ. Mr. Chairman, if I may?

Mr. PITTS. Go ahead.

Ms. ZDANOWICZ. I did want to just elaborate on one point that was made, and that is about the money that is used, the federal funding to lobby, and that is documented. You can find that in IRS reports and State lobbying reports that in fact federal funding is being used to lobby, and professionally, I have seen it done. I have been up against lawyers of protection and advocacy organizations lobbying in State capitals against State legislation. So it does happen, and it is not the original mission, and it takes away from what they are supposed to be doing.

Mr. WAXMAN. And it is in violation of the rules that say that they cannot use that money for lobbying.

Ms. ZDANOWICZ. And so I think that in order for them to be able to do what they are supposed to do, which is monitor like they did when you were being abused, I think that would be a significant improvement. So thank you.

Mr. PITTS. The Chair thanks the gentlelady and now recognizes Dr. Burgess 5 minutes for questions.

Mr. BURGESS. And please let the record reflect the generosity and time that I gave to the ranking member of the subcommittee. We don't often have areas of commonality, so I thought that was important to have that follow-up.

The majority of my questions were for Dr. Welner. One of my big objections to these types of hearings is we never have an M.D. Thank you for calling an M.D. Unfortunately, because of travel issues, he has not been able to join us, so I am going to submit my questions to Dr. Welner for the record.

Dr. Shern, your discussion with Ranking Member Pallone brought some things to mind, and really, this is more of just reminding people of the process, yes, the budget process, the legislative process, process in the agencies. Go back just for a little bit to the Mental Health Parity Act, and I don't know how many people now remember, the Mental Health Parity Act, introduced by one of our colleagues, Patrick Kennedy, indeed, we had hearings in this subcommittee many, many years ago. The Mental Health Parity Act was used as the vehicle to pass the Troubled Asset Relief Program, two absolutely unrelated proposals. Now, I just want to be clear. I actually opposed both of them, so that no vote actually did double service that day, but to think that we passed something of the magnitude of the Mental Health Parity Act and its effect upon caregivers and third-party payers as a vehicle to bail out banks, I am still bothered by that nexus. But nevertheless, that is what happened. The Mental Health Parity Act had not actually been scored, to the best of my recollection, by the Congressional Budget Office. I think it estimated some significant budgetary outlays over a 10-year period but be that as it may, now the Affordable Care Act actually passed sometime after that, about a year and a half after that, and was signed by the President in March of 2010. The part of the Affordable Care Act dealing with essential health benefits was actually subject to a rule. The rule was supposed to be published and concluded in August of 2012. I don't want to seem cynical here but the actual rule was delayed until a couple days after Election Day in 2012. I don't know why the Administration would see an advantage to doing that but apparently there was. And if you will recall, much of the difficulty that subsequently happened to the Affordable Care Act was because of that delay. The governors were required to disclose whether or not they would participate in state exchanges on November 18th. The essential health benefit rule was published on November 8th. So that gave them precious little time to actually evaluate, is this a good idea or a bad idea for my State. To be fair, they were given two extensions but finally by January 2013 the governors had to declare. Twenty-six States said no, thank you, we are not doing an exchange. Four States said well, maybe we will do one but we will let the Federal Government set it up. So the fact that so many States were not doing their own exchanges and that task then fell to the Federal Government and clearly the Center for Consumer Information and Insurance Oversight was not up to the task of standing up a massive new information technology project in the 8 months that they had available, and I think we all know the story on that.

But here is the issue. OK, Mr. Pallone is right. The Mental Health Parity Act and the ACA, the nexus of those two things does affect stuff. None of that—because the way the Congressional Budget Office works, we only get information about bills before we pass them. Sometimes we don't even get that. But we only get that budgetary information as the legislation is coming through the process. We don't get a rescore by the Congressional Budget Office when the rulemaking happens. So if you take the combination of the Affordable Care Act and the essential health benefits, when the Mental Health Parity Act was passed it said we are not requiring you, Mr. Private Insurance Company or Mrs. Private Insurance Company, to offer mental health benefits, but if you do, they need to be on a par with other medical services that you offer. So I am concerned that there were companies that were going to drop out of the mental health business. A year later, we had the Affordable Care Act passed and it says this is part of your essential benefit package.

I am from Texas. I will never attribute to coincidence that that can be adequately explained by conspiracy, but the Mental Health Parity Act was passed in 2008 and the rule was not published until last November, and I can't help but wonder if the reason the rule was not made public until all of the Affordable Care Act stuff was in place was because this is going to blow the cost way beyond anything that anyone projected for the Mental Health Parity Act or for the ACA. I don't know the answer to that question. I think it is one that we are going to have to ask our Congressional budget writers to help us with but it just underscores the difficulty of making budgetary decisions on these types of issues. There are always things in the future that will affect them.

Thank you, Mr. Chairman. I have rambled enough, and I will yield back.

Mr. PITTS. The Chair thanks the gentleman and now recognizes the gentleman from Texas, Mr. Green, 5 minutes for questions.

Mr. GREEN. Thank you, Mr. Chairman, and Dr. Shern, I think we are in agreement that our country has a long way to go to improve mental health systems. I am also from Texas but in an earlier life I actually did probate work, and one of my judges, who was a friend, appointed me to do mental health work, do the probable cause hearings and the commitment hearings, and it opened my eyes to the Texas mental health code, and actually as a State senator, we were able to change some of it.

I appreciate Dr. Murphy's leadership for many years on this issue. I have some concern about part of the legislation, the Medicaid IMD exemption. My concern is cost shifting from the State if the State does it to the Federal Government.

But I want to get to the follow-up on my colleague from north Texas. Dr. Shern, the Affordable Care Act included demonstration in 11 States to test whether undoing the IMD exemption for emergency psychiatric care and letting federal funds pay for the care in IMDs that States would concurrently provide would improve service to the population. It is my understanding we don't yet have enough information to know whether this demonstration is successful. My question is, it seems to me that before we move ahead and spend billions to supplant the State funds, we ought to see if this demonstration yields any positive results. Can you update us on any of those demonstration projects?

Mr. SHERN. I am not aware that evaluations have been completed. Our position would be quite consonant with yours. When that provision was discussed and been made part of the Affordable Care Act, there was a concern that looking at only one element in a system of care just really wasn't the appropriate way to think about how to build an effective community care system. And so we maintained and the law was enacted that this had to be evaluated as part of a system of care initiative. Our recommendation is that there be no changes to the IMD law until the results of that evaluation are complete.

Mr. GREEN. OK. The Congressional Budget Office, they haven't officially scored the provision. My understanding is, it is quite expensive, tens of billions possibly. If we had tens of billions of dollars to spend on improving the mental health system in the United States, how would we direct it and where should we really be looking to invest that money to see the greatest improvements?

Mr. SHERN. Well, I think that we have heard a lot this morning about the importance of assertive engagement-oriented outreach. Ms. Thompson talked about how important some of that was for her mom and how it would have been helpful had that continued when her mom came home. The committee heard in testimony from Dr. Arthur Evans, who runs the Philadelphia mental health system, about how critically important that there be funds available for crisis alternative services, for peer engagement and outreach services. We know a lot about what we can and should do, and I would much prefer to see those funds spent on fully developing a continuum of care in communities with assertive outreach and engagement.

Mr. GREEN. Well, I am familiar at least in Houston, Harris County, with some of the substantial reforms that have been made in the last 20 years, for example, our Harris County Hospital District. When I would first go see a client or a patient, it was literally dismal. It looked like a holding cell in the hospital. But they have created a diversion now to where you actually have committed to mental health treatment, and it is a partnership between the University of Texas where we have a psychiatric hospital in Houston, but it is doing better but we have less psychiatric beds in Houston, Harris County than we did in the 1980s. So that is our big concern.

I am pleased with Dr. Murphy's bill. It includes a provision to extend the liability for doctors who volunteer in behavioral health clinics. He and I have had legislation for a number of years. It has passed this committee and somehow the Senate doesn't do it. It would expand for our FQHCs and not just behavioral mental health clinics but our FQHCs where volunteer physicians could go in and be under the Federal Torts Claims Act, and that makes so much sense. While it is a good step forward in increasing the mental health workforce, much needs to be done to develop professionals.

Mr. Chairman, both on our Health Subcommittee and I know on our Oversight Committee Dr. Murphy is doing, there are a lot of examples of things happening all over the country based on local community success, and I think this panel shows that, that maybe we should, since we do have the Affordable Care Act and mental health parity issues, then maybe we ought to look at some of those examples from around the country and see what we can do to make sure we get the best bang for our federal dollar to help our States and the local communities, because, again, oftentimes it is our hospital districts that are providing some of that care.

So I appreciate it, and I yield back my time.

Mr. PITTS. The Chair thanks the gentleman and now recognizes the gentleman from Pennsylvania, Dr. Murphy, 5 minutes for questions.

Mr. MURPHY. Thank you. I want to thank all the panel for being here. I really appreciate your time.

A quick question to start off with. I am just going to ask each one of you if you have read the bill. Ms. Thompson? It is a yes or no.

Ms. THOMPSON. Not the whole bill.

Mr. MURPHY. All right. Dr. Shern?

Mr. SHERN. Not the entire bill.

Mr. MURPHY. Ms. Jensen?

Ms. JENSEN. I didn't hear the question.

Mr. MURPHY. Have you read the bill we are talking about?

Ms. JENSEN. Yes, I read the bill.

Mr. MURPHY. The whole thing?

Ms. JENSEN. Yes, the whole thing.

Mr. MURPHY. Thank you. Ms. Zdanowicz?

Ms. ZDANOWICZ. And yes, I have read the whole thing.

Mr. MURPHY. Thank you. Ms. Jensen, did anybody else in your testimony today advise you on things to say?

Ms. JENSEN. Of course not.

Mr. MURPHY. So I am not sure where you got this statement from, that it would make it harder to get housing and education. If there is a point in that bill where you feel that is, will you make sure you let me know? Because I want to fix that. Would you let me know?

Ms. JENSEN. I don't understand what you are saying, sir.

Mr. MURPHY. You had said in your statements that the bill would make it harder to get housing and education. If there is a place in the bill where that occurs, would you let me know, because I want to——

Ms. JENSEN. If you take PAIMI away, we have a hard time getting help with housing and education.

Mr. MURPHY. I don't agree, but thank you.

Dr. Shern, I am just not clear. Are you a clinician that treats patients?

Mr. SHERN. No, I am a research psychologist.

Mr. MURPHY. OK. Thank you. You said SAMHSA does not support programs that are anti-treatment. Are you familiar with the Alternatives Conference?

Mr. SHERN. I am.

Mr. MURPHY. Are you aware that Alternatives is short for Alternatives to Treatment?

Mr. SHERN. My interpretation of Alternatives, it is not alternatives to treatment, it is alternatives available for people to make choices about how to best engineer their recovery.

Mr. MURPHY. Do you think everybody is capable of making that choice?

Mr. SHERN. I think everybody is capable of understanding what is important to them.

Mr. MURPHY. Ms. Thompson referred to something called anosognosia. Do you know what that is?

Mr. SHERN. I have heard it described, yes.

Mr. MURPHY. OK. I am disappointed you don't know what it is. It is critically important, so I have to go into a little lesson here. If a person has a stroke on the right side of their brain, and on the left side, their arm doesn't work, a characteristic of that is if you say to this person try and move your left arm and they don't and you say I think you are having a stroke, you need to go to the hospital, that person may say it is no big deal, I don't know what that is all about, that is anosognosia.

About 40 to 50 percent of people with severe mental illness, schizophrenia, if shown a videotape of them hallucinating, delusional, they don't know who they are, they think they are the angel Gabriel, Jesus, whatever else, and if you say do think that is OK, they will say sounds OK to me, I don't understand the problem.

What Ms. Thompson is referring to for those people who are not capable of making decisions on their own to have someone else assist them so that they have a right to get better. Would you agree that such persons may need some assistance that they are not capable of making on their own?

Mr. SHERN. I think the way that you specifically have characterized the situation, people would meet the criteria for not being competent and——

Mr. MURPHY. Good. We are in agreement there. And do you think in the Alternatives Conference, which spends about $600,000 a year of taxpayers' money, do you think we should be paying for conferences that have things called unleash the beast: primal movement workshop, how to make collages, dancing, interpretive yoga or how to stop taking your medication? Do you think taxpayers should pay for that?

Mr. SHERN. I think it is very important that we have an open——

Mr. MURPHY. I am asking, do you think taxpayers should pay for those items when we are so short on funds? Do you think we should be paying for that for people who have severe mental illness?

Mr. SHERN. I think that it is very important that we have an open forum to discuss the various——

Mr. MURPHY. I appreciate that. I didn't ask you about an open forum. So I am going to take that as a yes and you are afraid to say yes.

Do you know in SAMHSA's—no, it is true. Come on. I want to have an open discussion. In SAMHSA's documents that describe their strategic plan, it is about 40,000 words, how many times does it mention the word "schizophrenia"?

Mr. SHERN. You know, I have not had an opportunity to count them.

Mr. MURPHY. Well, it is easy to count because the answer is zero. Do you know how many times it mentions the word "bipolar"? Zero. So when you say SAMHSA is focused on severe mental illness, my problem is, it is not, and when I had the leader of SAMHSA in my office and I said would you change anything, she said no.

So what I see here is, I think SAMHSA plays a very important role. I want to see it keep on doing that. But I want to make sure we get back to evidence-based care, and I am assuming you would be OK with that.

Mr. SHERN. Absolutely.

Mr. MURPHY. That if a program shows that it can work, make it work.

Mr. SHERN. Absolutely.

Mr. MURPHY. And let us do that, and why I am concerned here is that throughout the Federal Government, we have got money in the Department of Defense, Veterans Affairs, Education, HHS, who knows where else, and we have to make sure we have got programs that work, and the ones that work, expand them, and if they don't, eliminate them, and if they are redundant, merge them, and that is what I want to have happen with this bill.

On the parity issue, real quick, I just want to say that there is parity for people who have private insurance in the Affordable Care Act. There is not parity with Medicaid, so if you have more than 16 beds, you are not going to get it, and if you see two doctors on the same day, you are not going to get it.

The last question I want to address to Ms. Zdanowicz. Dr. Shern called the Journal editorial a gross mischaracterization of SAMHSA for leading an anti-psychiatry movement. Do you have any comments on that with regard to SAMHSA and providing money or grants to groups that fight treatment or discourage treatment?

Ms. ZDANOWICZ. Yes, and in fact, I have read many of the State applications for grants from SAMHSA, CMHS, and when you read those, you find very little reference to the most severely ill. Much of it is about, this is how we are going to get people out of State psychiatric hospitals. It is about how we are going to—if we just offer people what they want and make sure that we are really nice to them, that they are going to be just fine and it is going to settle their symptoms. But the question is, well, what if the person wants is a semiautomatic machine gun to shoot you because they think that you are the devil? Well, then what do you do? Well, then you call the police and you get them into jail, and if there was ever a form of coercion, that is it.

Mr. MURPHY. Thank you. I have to yield back.

Mr. PITTS. The Chair thanks the gentleman and now recognizes the gentlelady from California, Ms. Capps, 5 minutes for questions.

Mrs. CAPPS. Thank you, Mr. Chairman, and I would like to thank all of our panelists for your testimony today. I want to single you out, Ms. Jensen, because yours was so personal, and I appreciate that you are willing to tell your story.

Dr. Shern, mental health is an important issue that members of this committee on both sides of the aisle have a shared interest in addressing. I worked in our community in public schools before coming to Congress as a public health nurse and so I have had experience with this topic, and I am really pleased that today it is being discussed.

We heard from the testimony that there are some provisions in this bill that have widespread support and others that are perhaps problematic. I know that other members of the committee have also expressed interest in the topic and introduced legislation on mental health, and I hope that moving forward we can have an open dialog—the chairman just mentioned that—about all of the proposals and ideas.

That being said, Dr. Shern, are there any provisions not included in H.R. 3717 that you feel are important to the improving mental health system?

Mr. SHERN. Well, as we have said on a number of occasions, I think that understanding that a full continuum of engagement-oriented and assertive outreach services are critically important for effective services for people with severe mental illnesses. Additionally, and I think that Dr. Murphy mentioned this in his remarks or Mr. Pitts, we are continuing to learn about the importance of early identification for people who are going to develop disorders that have psychotic features, and I think it is critically important that we do a much better job at early identification of people who are going to have the more severe illnesses, and we are developing a reasonable evidence base about the things that are helpful to them because that can stem disability. I am also very excited about the peer movement, the use of persons who themselves are in recovery to help with these engagements and follow a long process, and also with appropriate supervision to provide the kind of extension of the mental health workforce that is going to be required.

Mrs. CAPPS. Yes. Well, that is the point I wanted to pick up on because Dr. Welner in his written testimony that I read, he noted the importance of having enough mental health professionals. Maybe that is a whole other hearing, particularly it seems to be a hole in this bill and one that I think we should be addressing with more specificity.

Dr. Shern, one of the key principles both sides of the aisle agree on is that we need to do everything possible to encourage individuals, and you talked about outreach, struggling with mental illness to seek treatment. That is actually part of the stigma, recognition and the clear sort of lack of understanding that we have about our brain and issues that affect it. Treatment does prove to be very helpful, as we heard today, and is more successful I think than some of the public seems to recognize, and early detection, just as you said, and regular treatment are so essential for preventing those rare and tragic cases where individuals become violent toward themselves or others, and we know people with mental illness are actually more likely to be victims, so that is a piece of the story that needs to be clearly said as well.

But the stigma demands, I think, and we should be desirous of ways to address the stigma. Privacy concerns are also intimately related. That is why I am concerned about the changes to our health privacy law that this bill proposes. It creates entire new standards for individuals who have what the bill loosely defines as serious mental illness, and that is a loose definition, unfortunately, and I know these are difficult areas to find the right path but that is something we really need to get to.

Dr. Shern, first, can you help us clear up a key point of fact? Does HIPAA always require patients to give their permission before information is shared or do providers have flexibility if there is a threat or if they believe the patient lacks capacity?

Mr. SHERN. It is my understanding that there is flexibility. You know, I was thinking also the Virginia Tech shooting, and when people looked at FERPA and HIPAA then, it was clear that there was a lot of misunderstanding about the bill and in emergency situations that can be found.

Mrs. CAPPS. Yes.

Mr. SHERN. So part of the thing I think we need, and I think Ms. Thompson would agree, is just better public education about what those laws actually mean.

Mrs. CAPPS. I am glad you put that on the record.

What impact will the changes proposed in the bill have on people's willingness? Is that a concern to you, people's willingness to seek treatment for mental illness?

Mr. SHERN. It is a concern of mine, a concern of my organization, given the coercive nature of some of the outpatient treatment programs.

Mrs. CAPPS. Thank you. I yield back.

Mr. PITTS. The Chair thanks the gentlelady and now recognizes the gentleman from New Jersey, Mr. Lance, 5 minutes for questions.

Mr. LANCE. Good morning, and thank you, Mr. Chairman, and thank you for your leadership on this issue, and thanks to Dr. Murphy as well for his leadership.

Earlier this week, a bill on which I had worked with Congresswoman Matsui of this committee, the Excellence in Mental Health Act, was included in a larger piece of legislation, and I am pleased that the President has signed that into law and I certainly want to work with all members of this subcommittee and the full committee as we move forward on this challenging issue.

Ms. Zdanowicz, as I understand it, your sister spent quite a few years in New Jersey facilities including the now-closed Hagedorn Psychiatric Hospital in Hunterdon County. I grew up in Glen Gardner where that facility was located. Before it was related to psychiatric concerns, it was related to tubercular concerns.

It is clear from your testimony that many mental health facilities in this country are currently unable to meet the needs of their communities. In your judgment, would passage of legislation in this regard help in States across the country including States like New Jersey?

Ms. ZDANOWICZ. Absolutely, and the closing of Hagedorn Hospital was a travesty. That is the hospital I mentioned that was a safe hospital that she was transferred to. She got excellent care there. And it was closed. And she then moved to Greystone which, as I mentioned before, is a gem. It is a wonderful hospital. But as a result of the closure of Hagedorn, it is virtually impossible to get anyone into a State psychiatric hospital now, and in fact, the State has implemented what I will call a gatekeeping process that prevents people—when a psychiatrist says this person needs to be in a psychiatric hospital because they need more than two weeks of treatment, they can be shut down by a nurse who is reviewing the process just because the State is trying to keep the population down.

Mr. LANCE. Before your sister was at Hagedorn, what was the State hospital before that where she was?

Ms. ZDANOWICZ. That was Ancora in south Jersey.

Mr. LANCE. In southern New Jersey, yes.

Ms. ZDANOWICZ. And it was a very bucolic setting. It was a very nice hospital when she first went there. There were less than 500 patients, and the care was very good until because of the closure of the previous hospital the population grew to 750 and it was truly bedlam because the hospital, the staff were not able to handle it and that was when I was able because I had the resources to get her moved to a safer hospital. But it wasn't until the Department of Justice came in at the request of the State and investigated it, protection and advocacy was nowhere to be found, and in fact, I called them at one point, but that was not on their radar screen. They were more concerned with other issues like legislation for AOT and fighting that.

Mr. LANCE. Thank you. Let me say that I was honored as a child to know Garrett Hagedorn, who was a State senator from Bergen County, and I had the privilege of being the minority leader in the State senate before I came here, and I have worked on these issues and hope to be able to continue to work on these issues here in Washington, and thank you for being with us today.

Let me say that there are, Mr. Chairman, community mental health facilities in the district I represent such as the Richard Hall Community Health Center in Bridgewater, Township, in Somerset County, and I hope that these fine efforts can continue and that we can work in a bipartisan capacity on this very important issue and we are reminded yet again so tragically of the importance of this issue based on what happened at Fort Hood yesterday.

Mr. Chairman, I yield back the balance of my time.

Mr. MURPHY. Would the gentleman yield?

Mr. LANCE. I certainly would.

Mr. MURPHY. I just want to point out, there are misunderstandings in the HIPAA law, and Dr. Shern, you have never been involved in a case and you shouldn't already have an opinion on it.

This bill does not undo HIPAA laws. It clarifies them, and we want to work on language. I have been talking with Representative DeGette on this too. We want to make it so that all those things that are also in the regulations that go along with the law are clarified. It doesn't change anything, but there are a lot of misunderstandings. Clinicians misunderstand this all the time, so we want to make sure work to clarify that, but it doesn't change the law. Thank you.

Mr. PITTS. The Chair thanks the gentleman and now recognizes the gentlelady from Virgin Islands, Dr. Christensen, for 5 minutes for questions.

Mrs. CHRISTENSEN. Thank you, Mr. Chairman. I want to ask some questions to Dr. Shern about the bill and its impact on SAMHSA because the bill makes some significant changes to the way the Federal Government's mental health investment is structured within the Department of Health and Human Services, particularly in Substance Abuse and Mental Health Services Administration. I want to make sure that I understand the impact these changes could have, particularly to the Community Mental Health Services Block Grant and programs of regional and national significance.

Dr. Shern, starting first with the mental health block grant, how would H.R. 3717 impact this program?

Mr. SHERN. Well, it is my understanding that the block grant would be moved to the Assistant Secretary's office and would have a different type of oversight than it currently has now, providing less flexibility to States, for example, in terms of how those funds are used.

Mrs. CHRISTENSEN. So do you support provisions in this bill that would condition States' receipt of block grant funding on newly established federal involuntary patient or outpatient treatment standards and specific criteria for outpatient treatment?

Mr. SHERN. No, we wouldn't support that.

Mr. MURPHY. Could the gentlelady ask him to clarify what that means because I am not sure.

Mrs. CHRISTENSEN. What do you mean? I asked if he would support the provisions that would condition the receipt of block grants on newly established federal involuntary inpatient or outpatient standards, and he said no, he would not.

Mr. MURPHY. But I am not sure he read or understood the section there. It would simply say that States—and I appreciate the——

Mrs. CHRISTENSEN. Is this not on my time?

Mr. MURPHY. I am sorry, ma'am. I was asking to yield. I was just trying to clarify. Thank you.

Mrs. CHRISTENSEN. If I have time, I will yield at the end.

As I am sure you are aware, SAMHSA has general authorities to conduct programs of regional and national significance in mental health and substance abuse prevention and substance abuse treatment. I understand funding through these authorities accounts for approximately 35 percent of SAMHSA's mental health budget and 25 percent of substance abuse spending. Title XI of H.R. 3717 would terminate any program by the end of the fiscal year that is not explicitly authorized or required by statute shall be terminated. So how will this impact SAMHSA's ability to continue initiatives pursuant to PRNS authorities like the Minority Fellowship program and National Suicide Prevention Hotline?

Mr. SHERN. It is my understanding that through the appropriation process, Congress can direct and influence SAMHSA's agenda. So in many ways, those kinds of relationships between the legislative and executive branch are already in place. The programs of regional and national significance are extremely important. Most of the innovative processes, particularly around systems of care issues and many of the things we are talking about today, have come through that program. So anything that would further constrain that, we would oppose.

Mrs. CHRISTENSEN. And in your testimony, you convey support for an initiative to improve interagency coordination of mental health and substance abuse programs within the Department but you seem to have some reservations about the way H.R. 3717 approaches coordination of HHS programs in mental health through the establishment of that new Secretary position. Could you elaborate on the reservations you might have about that?

Mr. SHERN. Well, our sense is that the Administrator for SAMHSA is a direct report to the Secretary of Health and Human Services, and so in some sense, interposing another layer of government between SAMHSA and the Secretary doesn't seem to us to be particularly helpful. Additionally, we believe, and I think this was mentioned earlier in testimony today, that it is a lot more than HHS that is involved in mental health care. Housing is involved, Justice is involved, Labor is involved, et cetera, et cetera, and we would concur with Drs. Richard Frank and Sherry Gleed in their analysis of the mental health system in this country saying that coordination needs to occur literally at the White House level because it is those interdepartmental issues which are important. Additionally, I think since President Bush's commission and its findings, there has been increasingly interdepartmental cooperation without imposing any additional structural changes to the government.

Mrs. CHRISTENSEN. Is there anything else you would like to add about any other areas the bill could negatively impact SAMHSA?

Mr. SHERN. Well, I think that sort of overbureaucratizing and overregulating and trying to more narrowly focus the agenda of SAMHSA around a particular set of concerns or issues which, generally, I think, are well represented already in their portfolio will not be helpful. Certainly, as in any human endeavor or any area of government, there are ways that things can be improved. I think that the organization has been mischaracterized in editorials and publicity surrounding that and that anything that can further those kinds of issues will be harmful to the people of this country and their mental health.

Mrs. CHRISTENSEN. Thank you. I yield back my time.

Mr. PITTS. The Chair thanks the gentlelady and now recognizes the gentleman from Louisiana, Dr. Cassidy, 5 minutes for questions.

Mr. CASSIDY. I yield to Dr. Murphy.

Mr. MURPHY. I thank the gentleman.

Dr. Shern, you already mentioned you didn't read the bill so is there a specific place in this bill that you can make reference to where you have these concerns about the Secretary of Mental Health and what that person will do to limit care? Is there some specific page or paragraph you can reference to clarify your conclusions?

Mr. SHERN. I am sorry, Dr. Murphy. I am not understanding the question.

Mr. MURPHY. Well, you made a statement to the gentlelady that this person who would be the Secretary of Mental Health would over bureaucratize and complicate some of these issues. Is there a specific place in the bill you can tell me where it says that? I need a specific. I don't need concepts or philosophy. Because what we are trying to do at this hearing is work to improve the bill. So if you think there is something in there, it is important this committee has accurate information and not impressions. Is there something in the bill? If you don't, you can get back to me on that. That is OK.

Mr. SHERN. The question I was responding to had to do with conditioning the receipt of block grant funds based on States having effective assisted outpatient treatment, and it is my understanding, and correct me if I am wrong, that that is in fact a provision of the bill.

Mr. MURPHY. There is a provision of the bill. That is not the issue with the Secretary of Mental Health.

Mr. SHERN. That wasn't the question, though.

Mr. MURPHY. Well, part of it. You said it would over bureaucratize. The person who now handles SAMHSA, do you know what her degree is in, what her background is?

Mr. SHERN. She is an attorney.

Mr. MURPHY. Exactly. Haven't we done enough with treating people with mental illness as legal cases? We have closed our hospitals and filled our prisons. We close our treatment centers. We have not given adequate funding to community mental health centers and we have replaced the hospital bed with a flophouse or a blanket over some steam grate. That is wrong. I think it is immoral. That puts us in a third-world category.

Mr. SHERN. I agree with you completely. I think it is one thing——

Mr. MURPHY. I want for the record—yes, there is a lot to do. A person's background should meet their role. Now, I respect that you are here, but also, it is important to understand, you don't treat patients. You have never been involved in a patient case. You have never been involved in a HIPAA discussion. You haven't, and that is important. You are here as a citizen. But I want to make it very——

Mr. SHERN. I am here as a research psychologist.

Mr. MURPHY. I understand, sir, but you haven't read the bill, OK? Sir, along these lines, let me clarify for the committee, the Federal Government spends $125 billion a year across many agencies. The Department of Defense has spent $100 million and the group just said that the money they spent on resilience programs and other things doesn't work. DOD has to go back and say what did we do wrong. Well, we found out that some of the things they are doing are in clearly good programs with regard to evidence-based programs, and some of it is not, and they need to make sure people are following the program. The VA spends a lot of money in mental health but unfortunately, a study said that about 20 percent of the time when someone goes into a VA hospital for mental health services for PTSD, they get appropriate care. The rest of the time they don't. That is wrong. Judiciary spends a heck of a lot of money and in many States on jails. That is wrong. We should be treating these people.

We have had many witnesses before this committee that do that. The purpose of the Secretary of Mental Health—and I think you are demeaning the quality of this. I don't want someone who is dealing with 60 million Americans that one out of five or one of four people who deal with it in life to be some back bench low-level person. I want this person to have some power and mojo. I want this person to be a clinician of an M.D., Ph.D. or D.O. level. I want this person to be one who has access behind their title, Assistant Secretary of Mental Health, to be able to walk into the office of Judiciary, Defense, the VA, Education, HHS and say we want your information, we need to know if your programs work or don't work or if they are redundant. We have got to make this system work.

Sir, for the last 20 years that SAMHSA has been around, it has gotten worse. Now, SAMHSA has done a lot of great things, and I applaud them for that, and we want to keep them going. I am not interested in getting rid of them. I am interested in beefing them up. But I am also saying we need evidence-based programs around this country.

There is a lot of misinformation being thrown out today, so I am frustrated, but I also know, you know what? That is the nature of the mental health community. For the first time since Kennedy was President, for the first time in the last 50 years we have an opportunity in this Congress to say we need to overhaul this system. There have been some great programs that have come through. I applaud Congressman Kennedy and Senator Wellstone. Some of those things have been marvelous. But it has been piecemeal, and I want us to really approach this in a comprehensive way but sometimes in the mental health community, we are so used to dealing with dysfunction in ourselves, we don't understand when we have an opportunity.

So here is what I am recommending. When you are given a comment and you haven't read the bill, say I haven't read the bill, OK? And with regard to this, what we want, what I want is from everybody and all the agencies throughout spreading rumors about this bill too to my colleagues and other people, send me ideas for amendments. Let us work on this, but let us not play this game.

Thank you. I yield back.

Mr. PITTS. The Chair thanks the gentleman and now recognizes the gentleman from North Carolina, Mr. Butterfield, 5 minutes for questions.

Mr. BUTTERFIELD. Thank you very much, Mr. Chairman, and thank the witnesses for their testimony today. I will try to look around Mr. Tonko and see all four of you. That is the advantage of being on the bottom tier. That is fine, Paul. That is fine.

But thank you for holding today's hearing. Certainly, mental health is a very important issue. It is an important issue to all four of you. It is an important issue to us and certainly to the people that I represent in North Carolina, and so that means that we have to do all that we can at the federal level to ensure that people who are living with a mental illness receive the treatment and support they deserve.

Some of my colleagues certainly know in my prior life I was a trial judge in North Carolina, served for 15 long years in 32 counties in my State, and so I have seen firsthand what mental illness can do not only to families but to communities, and so I thank you for your passion.

I have read most of Mr. Murphy's bill, and I think it is a good step, a step in the right direction. Certainly, there are many improvements that we can make, and I thank the chairman for offering us an opportunity to offer amendments to the legislation and there will be several.

There are many different people involved in the continuum of care for mental illness and it is important that we recognize another category, and that is the role of social workers in the continuum of care and the important role that they play in mental and behavioral health infrastructure in our country. The importance of the social work profession will continue to increase as the mental and behavioral health challenges impact a growing percentage of the population. According to the U.S. Bureau of Labor Statistics, the need for social workers specializing in mental health and substance abuse is expected to grow by 23 percent from 2012 to 2022. That is 10 years. That rate is much faster than the average for all other occupations. Social work is built on a foundation of integrated care working directly with patients, but in settings including hospitals and schools and substance abuse prevention and treatment programs and family service settings and long-term care facilities. Social workers have a history of working with and across disciplines including psychiatrists, pharmacists, nurses and others and will play a central role as we seek to improve health outcomes for people with mental and behavioral issues.

I understand that part of the goal of this hearing is to identify and fill gaps that exist in the health care workforce in an effort to meet the unique needs of different populations such as our veterans and people living in urban or rural communities or adults.

Let me go to Dr. Shern if I can very quickly. We know that health professions other than M.D.s and Ph.D.s have a growing role in meeting the mental health needs in the United States. Can you talk about your experiences and/or best practices working with other professionals in an integrated and team-based approach?

Mr. SHERN. Yes, well, I think that that integrated team-based approach that involves several different disciplines is essentially the state of the art in terms of how services are best delivered, particularly for people who have complex conditions or have, in this case, severe mental illnesses, and I think that there are real opportunities and real challenges that we confront in terms of adequate health care workforce in general and trying to understand and articulate different roles, particularly roles for paraprofessionals, peers and others and certainly including social work. You know, all of this that we are talking about in terms of the integration of care, understand that people live in communities, interact with complex systems, that is the hallmark of social work's approach to these issues. So I think many disciplines are involved. I think the best treatment involves a multidisciplinary team and I think that is basically considered state of the art in terms of services for people with severe mental illness.

Mr. BUTTERFIELD. How do you see an integrated team-based approach involving social workers and pharmacists and nurses and others in addition to psychiatrists contributing to the success of this legislation and addressing mental health needs?

Mr. SHERN. Well, it is clear from research actually that was done in the 1970s that multidisciplinary teams can both save money in terms of decreasing utilization of the most expensive resources and improve outcomes, and the disciplines that you mentioned in your question would be the disciplines that typically would be involved in those kinds of multidisciplinary teams.

Mr. BUTTERFIELD. Finally, let me go to you, Ms. Thompson, and thank you very much for your very passionate testimony. On another day I will share with this committee my personal story. I too grew up in a home with a mother who had mental illness. It was paranoia. She was not a harm or threat to anyone except herself, but it had a significant impact on her family and her work. So thank you for your testimony.

Do you think this legislation does enough to recognize and encourage an integrated team-based approach to addressing mental health needs of patients and their families?

Ms. THOMPSON. As I said earlier, I haven't read the entire bill. From my understanding, it addresses—the issue I have with what has happened in my experience was that there was no quality of life for my mother, so whatever it takes to create an ability for people to have a better quality of life, whether they know what it is or not, whether they are able to recognize it for themselves or not, that I feel we have an obligation to do that.

Mr. BUTTERFIELD. Thank you. My time is expired. I am sorry.

Mr. PITTS. The Chair thanks the gentleman and now recognizes the gentlelady from North Carolina, Ms. Ellmers, 5 minutes for questions.

Mrs. ELLMERS. Thank you, Mr. Chairman, and thank you to our panel. Each one of you has very important information for us today, and I would also like to congratulate and thank my colleague, Mr. Murphy, for the work that he has done on this issue, especially in relation to the HIPAA situation. As a nurse before coming to Congress, I know that much of the misinformation is parochial and it is misinterpreted or overinterpreted and the clarifications are necessary so that each health care professional can understand what can be relayed because it is a very crucial time.

So with that, I do have a question for Ms. Zdanowicz and for Ms. Thompson. Both of you are doing important work, and your stories are compelling on a personal level as well. In North Carolina, the past 10 years, the suicide rate has spiked significantly from about 18 percent to 22 percent. I represent Fort Bragg, and this affects our military, as you know, and our soldiers as well. In fact, a statistic that I am reading here that is provided for me says that actually this year into 2014, there have been more soldiers who have died by their own hand than those on the battlefield. Now, death in itself is not to be embraced. However, when we look at that statistic, we know the effects are incredible and that we need to deal with this issue.

Obviously, medical beds, or patient beds, and psychiatric beds are so essential, and we are in more need today than ever. Today, North Carolina has only eight beds in a State psychiatric hospital per 100,000 people. So I believe we are at the lowest ratio, and one of our largest hospital systems in my area of North Carolina, Wake Med, is basically struggling with this issue. They treat an average of 314 patients a month whose primary diagnosis is psychosis, and this is up one-third over the last 2 years. Any given time, there are 25 to 50 patients with a diagnosis of mental illness of some form that are not necessarily in a dedicated psychiatric unit but are having to be placed in other areas of the hospital, and as you can imagine, that is difficult for the patient, the family and then also the health care professionals who are taking care of them.

Ms. Zdanowicz, can you give us some points and guidance on how we can improve this mental health bed situation?

Ms. ZDANOWICZ. Well, I would love to tell you that we could convince States to increase the number of beds and increase the number of long-term and intermediate-care beds that are just disappearing but that is not going to happen, and that is why assisted outpatient treatment is so important because it is a way of keeping individuals who are not safe in the community without medication on treatment, and there is empirical evidence to show that it reduces hospitalization, reduces incarceration, which, as I mentioned before, the jails and prisons are the new State psychiatric hospitals. If we don't have those kinds of facilities, we have to have a way of ensuring that people who don't realize that they are ill, that won't take their medication any other way have a means of getting that support, and it is not just a court order of somebody telling them. It comes with services. And I know people who have experienced it, and it does not scare people away and in fact it improves their lives. So unless we can get more beds, this is a solution with the population we are talking about, not everyone but the population we are concerned about.

Mrs. ELLMERS. Thank you.

And Ms. Thompson, I just want to thank you for the work that you are doing. In Randolph County, which is one of my counties that I represent, the crisis intervention training for law enforcement is making a significant difference. Basically this is sponsored by you and NAMI, and it has been incredible work in the ability to have those law enforcement officers in the situation, know when they have to react and be able to engage and deescalate the situation, and it has made a huge difference. However, we need to continue to show that this program is working and we need greater coverage and reaching out to some of the other law enforcement. How can we extend this program? Do you know of the barriers? I know I am running out of time, but can you identify the barriers that we can address that might actually be able to help this situation?

Ms. THOMPSON. The situation in terms of getting more people informed?

Mrs. ELLMERS. Yes, or getting this program in place for more law enforcement to learn about——

Ms. THOMPSON. This program is vital. You need to give people the tools on how to deal with people in crisis, because if you don't, that is where the abuse comes from. That is really the abuse in the police department. That is where all of that comes from is because you are asking them to deal with something that they have no knowledge, that is not their skill set, and it is not fair to them and it is not fair to the individual.

But that needs to be funded. I mean, there is no way—we can't do it alone. NAMI is trying desperately. We are a volunteer-based organization. We are a nonprofit organization. We try to reach out to law enforcement as much as we can. We need help. We need funding.

Mrs. ELLMERS. Thank you so much, and again, thank you to our entire panel.

Thank you. I yield back the remainder of my time.

Mr. PITTS. The Chair thanks the gentlelady and now recognizes the gentleman from Florida, Mr. Bilirakis, 5 minutes for questions.

Mr. BILIRAKIS. Thank you so very much, Mr. Chairman. I want to thank the panel for their testimony and of course coming to Washington and sharing with us.

In addition to being on the E&C Committee, I also serve as Vice Chairman of the Veterans' Affairs Committee, and we have held several hearings over the years on the mental health issues and of course, it is an extremely important issue. As a matter of fact, Time magazine wrote back in 2012 that "more U.S. military personnel have died by suicide since the war in Afghanistan began than have died fighting there." When they take their own lives, these deaths diminish us as a whole. It leaves behind spouses, children, parents, and siblings who must deal with the loss and their own grief.

So when I look at H.R. 3717, and thank you, representative Murphy, for filing the bill, the Helping Families in Mental Health Crisis Act, I look at it from the viewpoint of our veterans and their families, in addition to the general population.

I want to thank the witnesses again for coming here today and talking about these issues. It is so very important. It is an invisible wound that millions grapple with each day. It carries a stigma, as you said, and we need to help remove the stigma so people aren't afraid to seek help. Mental health issues are just as serious as visible physical wounds, in my opinion. We must responsibly address this problem. Too many Americans and their families are suffering, and they deserve proper care, in my opinion.

Your experiences dealing with family members with mental health issues, or living with it, or treating it helps inform a lot of us in the debate. Again, thank you for being here. I really appreciate it.

And I would like to yield the rest of my time to Representative Murphy.

Mr. MURPHY. I thank the gentleman for yielding.

A couple other clarifying points I want to make for members. This bill does not cut 85 percent of federal funding for the programs. It does not. There are multiple sources for that federal funding. This is one of them. And so it is very important that people are dealing with the facts.

Also, Dr. Shern, you referred to a coercive feature of assisted outpatient treatment that would make people seek treatment. Are you aware of the programs Ms. Zdanowicz is talking about here with regard to the evidence on when AOT can work to reduce incarceration, et cetera?

Mr. SHERN. Yes, I am.

Mr. MURPHY. So what I am trying to find out here, and I recognize not all States do things the same way.

Mr. SHERN. Right.

Mr. MURPHY. For example, California has one county that does this; the rest don't. And some States do it better than others. I think New York does a pretty good job on that.

But in this bill, are you aware of how we define who would qualify for assisted outpatient treatment?

Mr. SHERN. Generally, yes.

Mr. MURPHY. Well, we very narrowly defined that. They to be incarcerated before, had multiple hospitalizations, but the rest we leave up to the States because I think States should decide a lot of this too. So I want to make sure we are making it clear. There is no coercion involved here but we are saying States have to have something on the books.

But let me ask the panelists this——

Mr. SHERN. Can you clarify that a bit, the no coercion involved in assisted outpatient treatment?

Mr. MURPHY. I am saying with regard to the States, they can put this together any way they want but we are saying——

Mr. SHERN. Coercion of the States?

Mr. MURPHY. Yes. What we are saying here is that as an alternative to just waiting until someone is in imminent danger, until someone has a knife to their head or someone else's. We want to provide a mechanism by which people are not just waiting for that "someone is about to die" standard. That is something established in the 1700s. We need to be doing more.

So what I want to ask here is, I am open to other ideas, and what else could we do to make sure people—we have this integrated care, this wraparound care. I mean, we know when someone is in an acute crisis, that they need a lot of help and long term. What would be a couple of those things? Ms. Thompson, can you think of anything that we should make sure we include here?

Ms. THOMPSON. Well, I think how HIPAA is addressed is vital because, you know, waiting until somebody is at a risk to themselves and others is waiting way too long to help them. We are waiting way too long to step in.

Mr. MURPHY. So making sure we have some way that families can participate more would be helpful?

Ms. THOMPSON. That is correct.

Mr. MURPHY. Dr. Shern, do you have any recommendations of ways we could help provide some integrated wraparound services? I mean, we have some in here now under the Excellence in Health Care. You don't have to answer now but if you can provide us some ideas, I would love to hear them.

Mr. SHERN. Sure, and I think we have a pretty good evidence base with regard to that and I think that where AOT has been shown to be successful is in New York where there was a $125 million appropriation to enhance services.

Mr. MURPHY. Ms. Zdanowicz, do you have any other suggestions that we can do? I know you are in support of AOT but any other things States should be doing?

Ms. ZDANOWICZ. Well, I mentioned earlier, I just finished a survey of jails and prisons around the country, and this is where we need more help, and it is something that is being overlooked. I think it is coming to the forefront now. But that is where are so many people with mental illnesses who are refusing treatment, and what happens to them in those situations, I have talked to jails and learned just how horrible and dangerous and heartbreaking it is, and I think it is something that we have to focus on and not only just providing treatment in the institutions but keeping them out of the institutions, and I have talked to police officers trained to deal with people with mental illness. I was in a meeting where they asked, after hearing all the evidence, you know, the recovery-based peer support programs the State provides, a police officer stood up and said well, when I call the State, I can't get any help for this homeless person who is psychotic and delusional. So I think those are the areas that we need to have more integrated services.

Mr. MURPHY. Mr. Chairman, for the record, I just want to point out that in support of what Dr. Shern is saying, a report says that ACT works but a report says we also found evidence in the case manager data that receiving AOT combined with ACT services—assertive community treatment—substantially lowers risk of hospitalization compared to receiving ACT alone. So we will work with you on that. Thank you.

Mr. PITTS. The gentleman yields back. The chair now notes that the subcommittee members have concluded their questions, and without objection, the Chair recognizes the gentleman from New York who is also on the full committee, Mr. Tonko, 5 minutes for questions.

Mr. TONKO. Thank you, Mr. Chair.

Preliminarily, I state to our colleague and my friend, Mr. Murphy, that many of us are engaged in regard to this bill. We have read the bill and have sent you specific suggestions on how we believe the bill can be improved. We all agree that there are serious issues that need to be addressed but there are also serious reservations out there to some provisions in the instant bill. I think your intent is right, and we want to continue to work with you, but it needs to be a collaborative process. I commit to keeping an open dialog here so as to exchange on behalf of the issues and to recognize the importance of the issues here, the people most importantly impacted by mental health disorders and mental illnesses are of high need. So we need to recognize that and move forward with the sense that more than one point of view needs to be exchanged here in order for us to move forward most effectively.

I also want to make the record clear that the protection and advocacy organizations are already precluded, prohibited by federal law from using any federal funds for lobbying purposes. Any lobbying activities conducted by these organizations, most notable organizations, are done with private dollars. Certainly, this would be restricted as lobbying activities with private funds which as I am sure my colleagues on the other side of the aisle would agree with in the way of yesterday's Supreme Court ruling could raise significant free-speech concerns, and I think those free-speech concerns are essential here for these organizations using private dollars.

With that being said, I thank you again, Mr. Chair, for the opportunity. This issue is near and dear to my heart. I served in the New York State Assembly before coming to Congress. One of my proudest achievements in 25 years of service in that body was Timothy's Law. I was the prime sponsor of mental health parity in New York. I have the utmost respect for the mental health community and for those who advocate. Their resilience, their determination is stellar, and I recognize that, and I recognize the work done by the Oversight and Investigations Subcommittee to examine issues surrounding mental health.

While there are many aspects of this bill with which I strongly disagree in its current form, I think that the intent is right on and it is in the right place, and I hope that we can continue to have bipartisan discussions to improve the bill. Those struggling with mental illnesses deserve nothing less.

So Mr. Shern, in your testimony you speak to the fact that our treatment systems should be welcoming rather than frightening. I couldn't agree more. And I think everyone in this room recognizes that voluntary community-based treatment is always preferable and leads to better outcomes in the long run.

One of the more difficult questions we are weighing as a panel is what circumstances more coercive forms of treatment, whether this is assisted outpatient treatment or inpatient hospitalization might be necessary. In your opinion, when is it appropriate, if ever, to resort to these more coercive forms of treatment when dealing with an individual with serious mental illness?

Mr. SHERN. Well, I think, in situations in which a person doesn't have the capacity to make the decisions necessary to preserve their safety or is a threat to another person, which is the standard sort of commitment that laws that exist across the country. At that point in time we have provisions for involuntarily treating individuals. When we implemented our New York City program, our Manhattan program for people who had severe mental illnesses and were living on the streets of New York, I personally witnessed people literally running from our program because of—literally running, jumping onto the Staten Island Ferry by slipping under the door right before the ferry took off rather than be engaged by our program. So I personally have experienced people running from care because of coercive interventions.

Mr. TONKO. And Mr. Shern, does the evidence show that assisted outpatient treatment programs are more effective than similarly resourced assertive community treatment programs?

Mr. SHERN. It is my understanding that those situations in which AOT has been shown to be effective both in the Duke trials and in the New York State experience were situations in which there were enhanced services available. Compelling people into a service system that doesn't exist is not going to make a difference.

Mr. TONKO. And when States have adopted more expansive need-for-treatment standards for civil commitment, have we seen an impact on individuals seeking care voluntarily?

Mr. SHERN. Coercive interventions can chase people from care.

Mr. TONKO. Thank you very much, and with that, I yield back as I see I have exhausted my time.

Mr. PITTS. The Chair thanks the gentleman. The Chair overlooked one member of the subcommittee, so at this time yields 5 minutes to Mr. Griffith from Virginia.

Mr. GRIFFITH. Thank you very much, Mr. Chairman, and I apologize to both you, Mr. Chairman, and to our panelists. I have been involved in another hearing as well and so I have been running up and down the stairs trying to make sure I got here.

I want to agree with Representative Tonko in saying that putting this forward by Dr. Murphy is a big step. Somebody has to put it forward. We have been studying it for a little while. He decided to take that leap, and I commend him for that because that is very, very important. There are things in a bipartisan fashion that we can work on to improve the bill, and I heard Dr. Murphy say earlier he is looking for those suggestions.

That being said, I also want to underscore that HIPAA does have to be addressed. It doesn't mean we want to undo the principles of HIPAA. It doesn't mean we want to, you know, let everybody have access. But we heard so much testimony from so many family members who wanted to help, people who loved the individual with mental health problems who wanted to be there for them, and in many cases were not able to be there to take care of them because they were blocked. They were blocked from having the necessary knowledge to know whether or not they were a risk to themselves or to others. They were blocked because they didn't know exactly what was going on. So we have to improve that.

Where I would like to see improvements in this bill is in figuring out how to define that because when you look at Section 301, we have a real opportunity to work on that across the board, all parties coming together and figuring out how we do that. My concerns particularly relate to two groups of individuals. You have got the elderly. It is pretty obvious that with an elderly person, if you have competing children—I used to do divorce work in my small town private practice. I did a lot of criminal work. People will fight over all kinds of things and particularly when it becomes mom or dad, family members get into a fight. So we have to figure out a system where if you have got a child who hasn't been involved in mom's life for 20 years, that they don't come waltzing in and knock Ms. Thompson out because all family members get it.

Also, I worry in that same situation, that young men, we have heard so much testimony that young men particularly in that suspect group, 14 to 18 is a problem but 14 to, I think it was 28—Dr. Murphy can correct me on my ages—where there is a lot of onset of first signs of mental illness and they don't get treatment. Fourteen to 18, parents are still involved. On that 18th birthday, they get knocked out. And whether that is what HIPAA is supposed to do or not, it is the way it is interpreted, and if you are worried about a lawyer suing you for giving away the information, you are not going to do it as a doctor. No matter what different people may think it means, Dr. Murphy is right. We have got to clarify it. But then I also worry if you have too big a door for people to get information, does that estranged father come back in, never having participated in his son's life and now the son is 22 and he decides he wants to come in and knock mom out.

So that is the scenario that I am looking at. I think we can make improvements. And with that, Mr. Chairman, I yield to Dr. Murphy.

Mr. MURPHY. I thank the gentleman. I also thank you for your commitment to help us improve that language. It is important. We have had too many people raise concerns so we have to do it the right way.

Dr. Shern, you had mentioned that you are aware—well, let me ask you, are you aware of any study at all, empirical, published study, that supports your understanding that broader commitment standards drive people away from seeking treatment? Are you aware of any particular study offhand or can you provide that for us?

Mr. SHERN. I can look into it. I am not aware of any offhand.

Mr. MURPHY. OK. I appreciate that, because you made the statement. I want it backed up with evidence.

I also want to say that what I was reading before, the quote I forgot to reference is where it said that AOT combined with ACT services substantially lowers risk of hospitalization compared to receiving ACT alone. This is the study done by Duke University Policy Research Associates and the University of Virginia School of Law on the New York State assisted outpatient treatment program evaluation. So there is a lot we can learn from New York.

One other thing I want to mention, when I refer to some of the concerns I have, and Ms. Jensen, you brought a very compelling story forward on what happened with that horrible place you were in, and I am glad you fought hard to shut it down, but also some of these groups also cause some problems too. A case we heard was from Joe Bruce. His son William was diagnosed with some psychosis. He was in Maine. And these advocates came in. This family was completely cut off from being able to talk to their son, which is a HIPAA issue, yet these advocates could talk to him, coached him during a hearing on this, and told him to say when he was asked if he was going to be a harm to himself or someone else say no. He listened to their coaching. He was dismissed from the hospital. He went home. He took a hatchet and chopped his mother to pieces.

This was very moving testimony this committee heard. We don't think a group like this has any business telling someone get them out of treatment altogether. We want professionals involved who are looking out for the best interest of the patients all the way through.

Mr. Chairman, I want to thank you for this hearing today. We have heard some powerful information. I look forward to working with my colleagues on both sides of the aisle on this. The good news is, we have elevated this to the level of Congressional discussion instead of keeping it in the dark shadows. We have understood that this isn't just an issue of violent mentally ill. We have to work together. I am excited about this, and I want to leave with a message of hope for the many people who are struggling with mental illness. We will continue to listen to you. We want to work together. We have got to change this system and help you all.

With that, I yield back.

Mr. PITTS. The Chair thanks the gentleman, and thanks him for his leadership on this issue. This has been a very important hearing, very compelling testimony, very informative. Thank you very much to the witnesses for coming.

Now, we have members who may have follow-up questions who were not able to attend. They are in other hearings. We will send you the written questions. We ask that you please respond promptly. Do you have something?

Mr. TONKO. Yes, Mr. Chair. We ask that these documents be included in the record.

Mr. PITTS. We have a unanimous consent request to include in the record testimony of the National Disability Rights Network; a letter from the American Psychiatric Association; testimony by the National Coalition of Mental Health Recovery; testimony titled Helping Families in Mental Crisis Act, H.R. 3717 by the Citizen Commission on Human Rights[*]; a letter by Consortium for Citizens with Disabilities; and testimony by Judge David Bazelon Center for Mental Health Law. Without objection, so ordered.

[The information appears at the conclusion of the hearing.]

Mr. PITTS. I remind members that they have 10 business days to submit questions for the record. That means members should submit their questions by the close of business on Thursday, April 17.

Thank you again very much for attending. Without objection, the subcommittee is adjourned.

[Whereupon, at 12:48 p.m., the subcommittee was adjourned.]

[Material submitted for inclusion in the record follows:]

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[*] The information has been retained in committee files and is also available at *http://docs.house.gov/meetings/if/if14/20140403/102059/hhrg-113-if14-20140403-sd008.pdf*.

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April 3, 2014

The Honorable Fred Upton
Chairman
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U.S. House of Representatives
2125 Rayburn House Office Building
Washington, DC 20515

The Honorable Henry A. Waxman
Ranking Member
Committee on Energy and Commerce
U.S. House of Representatives
2322A Rayburn House Office Building
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The Honorable Joe Pitts
Chairman
Energy and Commerce Health Subcommittee
U.S. House of Representatives
2125 Rayburn House Office Building
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The Honorable Frank Pallone, Jr.
Ranking Member
Energy and Commerce Health Subcommittee
U.S. House of Representatives
2322A Rayburn House Office Building
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Dear Representatives Upton, Waxman, Pitts and Pallone:

I write on behalf of the American Psychiatric Association (APA), the medical specialty association representing approximately 35,000 psychiatric physicians and their patients and families, to express appreciation for convening today's important hearing on H.R. 3717, the Helping Families in Mental Health Crisis Act. Over 60 million Americans live with a diagnosable psychiatric or substance use disorder, and 13 million Americans live with a serious or severe psychiatric disorder. Our country is at a historic crossroads in its treatment of individuals with serious mental illnesses and its ability to deal with the personal, economic, and moral consequences of untreated psychiatric disorders.

Both comprehensive mental health reform legislation and vigilant federal oversight to ensure that current mental health laws achieve their goals are important first steps to ensuring access to appropriate mental health care for millions of Americans. Access to innovative and integrated treatment must be increased in all appropriate venues of care, including community settings, psychiatric hospitals, and general medical institutions. Criminal justice reforms that encourage diversion from jails and prisons into safe, sensible environments for treatment must be continued and improved. Research into the causes and potential treatments of psychiatric conditions must be supported. Prevention and mitigation of the severity of mental illnesses must be promoted. An acute psychiatric workforce shortage must be addressed. Federal government mental health resources within the Department of Health and Human Services and beyond must be better coordinated, and more psychiatric expertise is needed. Finally, the promise of Congress' most significant bipartisan mental health reform in decades, the Mental Health Parity and Addiction Equity Act, must be kept.

The Helping Families in Mental Health Crisis Act seeks to achieve many of these goals, and it is clear that the legislation under review by your committee today contains an overall emphasis on the provision of evidence-based psychiatric and substance use services and research supports. In the wake of the Newtown shooting tragedy, both parties in both chambers have recognized a need for a thorough response to the tragedy of untreated mental illness. It is APA's hope that lawmakers in both parties, in collaboration with the mental health advocacy community, can move forward with bipartisan comprehensive mental health legislation that significantly and positively reforms our broken public health delivery system. Today's hearing is a serious step towards that end.

Recent progress has been made to improve access to treatment for individuals suffering from mental illness that both exemplifies the bipartisan nature of the nation's core mental health delivery challenges and inspires optimism for enactment of comprehensive reform. Legislation that temporarily delays cuts to Medicare physician reimbursement also included two important provisions that would support community mental health services and assist states with programs aimed at preventing hospitalization for individuals with severe and persistent mental illness. While APA was disappointed that the underlying legislation did not permanently address the flawed Medicare Sustainable Growth Rate formula, we were pleased to see inclusion of grant program for assisted outpatient treatment and funding for community behavioral health centers. APA is hopeful that bipartisan efforts, such as this, will continue in order to address the many remaining challenges persons with mental illness experience.

Thank you again for holding this important hearing. The leadership and members of APA look forward to working with you to better our patients' access to needed psychiatric services.

Sincerely,

Saul Levin

Saul M. Levin, M.D., M.P.A.
CEO and Medical Director

cc:
The Honorable Tim Murphy

THE WALL STREET JOURNAL.

The Definition of Insanity

How a federal agency undermines treatment for the mentally ill.

Review & Outlook
March 31, 2014

Every time a mass shooting happens in the U.S.—Sandy Hook, Virginia Tech, Aurora—we have the same national discussion: Why can't we identify and treat the dangerously mentally ill before they kill? Here is one infuriating answer.

Inside the U.S. Department of Health and Human Services sits an agency whose assignment since its creation in 1992 has been to reduce the impact of mental illness and target services to the "people most in need." Instead the Substance Abuse and Mental Health Services Administration, known as Samhsa, uses its $3.6 billion annual budget to undermine treatment for severe mental disorders.

Health professionals agree on the need to provide medical intervention for serious psychiatric disorders—schizophrenia, bipolar disorder, severe depression. The National Institute of Mental Health does evidence-based research and promotes medically driven models of care, including early intervention, intense psychiatric treatment and drugs. Doctors have promoted reforms such as "need for treatment" standards in civil-commitment laws, or assisted-outpatient laws so courts can require the mentally ill to receive treatment to avoid hospitalization. These reforms help the mentally ill and reduce crime, incarceration and homelessness.

Instead of being part of this solution, Samhsa is in the vanguard of the legal-advocacy and anti-psychiatry movement that sprang to life in the 1980s, and it continues to waste taxpayer dollars on programs that undercut efforts to help the world's Adam Lanzas.

Known generally as the "consumer/survivor" movement (as in having "survived" psychiatric treatment), this movement largely opposes drug treatment, psychiatric care, civil-commitment laws or even the reality of mental illness. Samhsa pushes the "recovery model," an approach that puts the patient in charge of crafting his own recovery plan and stresses "empowerment" and coping rather than medical intervention.

For instance, Samhsa's Guide to Mental Illness Awareness Week suggests schools invite as speakers such radical organizations as MindFreedom, which rejects the existence of mental illness and stages "human rights" campaigns against drug treatment and commitments. Or the National Coalition for Mental Health Recovery, which "holds that psychiatric labeling is a pseudoscientific practice of limited value in helping people recover."

THE WALL STREET JOURNAL.

Samhsa underwrites the Alternatives conference, which in 2013 included a session titled "Dance Your Way to Wellness and Recovery" and a presentation from the "Hearing Voices Network," which "believes that hearing voices is a part of human experience."

The recovery model can help people with minor mental illness. But Samhsa's allegiance to it neglects or harms individuals with severe psychiatric disorders. Most of Samhsa's annual $460 million in grants goes to community mental-health centers aimed primarily at the "worried well."

Samhsa's grants prioritize "prevention"—though there is no known way to prevent severe mental illness. Samhsa spends millions on anti-bullying coloring books and online kids games and pamphlets on how to handle emotional distress after floods: "Take care of pets . . . Nature and animals can help us to feel better when we are down."

E. Fuller Torrey, who runs the Treatment Advocacy Center devoted to helping the severely ill, has noted that Samhsa's most recent long-term planning document is 42,000 words but contains not one reference to bipolar disorder, schizophrenia or schizoaffective disorder.

Sally Satel, a psychiatrist who served on an advisory committee to Samhsa, told a House committee last year that her review of the 288 programs on the agency's registry of "evidence-based" programs turned up only four aimed at severe mental illness. Most were aimed at helping substance abusers, or enhancing parenting skills, or helping kids recognize "anxiety." Samhsa had even refused to put assisted outpatient therapy on the list, though this is the most-effective program for severe illness.

Ms. Satel told the House how Samhsa leadership routinely rejected advice from the medical professionals on its advisory council. Jeffrey Geller, the director of public sector psychiatry at the University of Massachusetts Medical School, related to Dr. Satel: "Most members who served [on the Samhsa advisory council] during the years I served gave up attempts for meaningful input and left in disgust."

Pennsylvania Rep. Tim Murphy spent a year reviewing federal mental-health policies and in late 2013 introduced a thoughtful overhaul. One proposal would create a new HHS assistant secretary for mental health to streamline federal programs and take over Samhsa's grant-making—requiring that money go to evidence-based practices. The position would have to be filled by a medical professional.

Some conservatives oppose this new government position, but the status quo is worse—and dangerous. Samhsa is out of control and would be better off abolished. But if that can't be done, the Murphy bill would reorganize government to make it more effective and accountable. And as long as the government spends billions on mental health, it needs someone to streamline and make more effective its dozens of programs.

At the very least, someone needs to assure Americans that their tax dollars aren't feeding a culture of nontreatment. The risk to society from untreated mental illness is tragically obvious. It's well past time for Washington's politicians to clean up HHS's absence of oversight at Samhsa.

RESPONSE TO NATIONAL DISABILITY RIGHTS NETWORK "TALKING POINTS" MEMO CONCERNING THE BRUCE MURDER CASE IN MAINE

By Robert (Joe) Bruce

The National Disability Rights Network ("NDRN") has published a misleading "Talking Points" memo as part of its lobbying campaign to oppose enactment of HR 3717, the bill that Congressman Tim Murphy has introduced to make important and needed reforms in the treatment of severely mentally ill Americans. As part of this campaign, NDRN has disavowed their member's responsibility for actions that led to my wife's death and my son's incarceration, and has suggested that my testimony to Congress in May 2013 was misleading. This response sets forth the truth, and also shows why HR 3717 should be passed as proposed.

Summary

My untreated, seriously mentally ill son William was dangerous and psychotic in 2006. After intense work, his mother and I were finally able to have him hospitalized in Maine's Riverview Psychiatric Center. However, lawyers from the NDRN affiliate in Maine, Disability Rights Center of Maine ("DRC") quickly stepped in to "free" him from the hospital. DRC's general counsel, Helen Bailey, and a DRC patient advocate named Patricia Callahan caused him to be released prematurely and with no supervision. Their actions led directly to his subsequent hatchet killing of Amy, my beautiful and beloved wife and the 47-year-old mother of our three sons. NDRN concedes this was a "horrendous tragedy" and doesn't deny DRC Maine's responsibility outright; rather, it merely seeks to blur it with "Talking Points."

After Will's incarceration, I became Will's legal guardian, despite efforts of DRC to prevent it. I obtained Will's medical records. They reveal that DRC in fact *caused* the "horrendous tragedy" my family experienced, as I show below. First, however, I discuss why HR 3717 is such an important bill, and should be passed.

HR 3717 Contains Important Fixes That Could Prevent What Happened to My Family From Happening to Others.

It is obvious that legislative action is needed. Once the advocates were empowered by PAIMI in1986 to enter into the treatment system to prevent abuses of vulnerable mentally ill Americans, they used their position to take on "additional and legally impermissible responsibilities that Congress never envisioned or authorized."[1] HR 3717 would restore the balance that Congress tried so carefully to strike in 1986, in several ways.

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[1] Amanda Peters, *Lawyers Who Break the Law: What Congress Can Do to Prevent Mental Health Patient* Advocates *From Violating Federal Legislat*ion, 89 Ore. Law Rev. 133 (2010) (hereinafter, "*Lawyers Who Break the Law*") *available at* http://mentalillnesspolicy.org/myths/mental-health-bar.pdf.

Lobbying by PAIMI Organizations Prohibited. In the wake of Amy's death I worked to reform the laws in Maine, including the passing of an Assisted Outpatient Treatment Law (AOT Law). AOT Laws like Kendra's Law in New York give the treating doctors and hospitals another option in between commitment and release, and have worked well in the states where they are in force. To my shock and utter surprise, DRC *lobbied against the AOT Law* (and did so dishonestly)! Prof. Amanda Peters noted:

> Maine's P&A system, the Disability Rights Center, has lobbied against provisions that would allow families and law enforcement officers to petition a court to initiate civil commitment proceedings. It has also lobbied against laws in Maine that would loosen patient confidentiality restrictions for family members and allow patients to be medicated over their objections.[2]

The AOT Law passed in Maine, but NDRN's affiliate members are consistently opposed to legislative reforms of the current system. HR 3717 would prohibit PAIMI funded organizations from lobbying altogether and is a much needed reform.

Systemic Litigation by PAIMI Organizations Prohibited. When they can't defeat legislation they sue to block it. HR 3717 would prevent PAIMI funded organizations from engaging in such "systemic litigation" and attempting to get from the courts what they failed to achieve in the legislature.

Interfering With Doctor-Patient Relationship Prohibited. As is obvious from Will's case (see examples below) advocates openly counsel patients contrary to their doctor's advice. In Will's case he was counseled that it was his "right" to refuse medication – as if a person lacking insight has any meaningful "rights" when it comes to refusing medication that will restore his insight. Will himself now knows that medication can do much good. Tragically, the actions of his "advocates" prevented him from experiencing the improvement and healing medication would have brought.

HIPPA Privacy Restrictions Eased. Amy and I were excluded from Will's treatment meetings and so she never knew what the advocates were saying about us ("a negative force in his life" – see below) or that he was being counseled not to take medications. Our presence in those meetings could have prevented a tragedy. HR 3717 would allow physicians to exercise good judgment and allow caregivers into the meetings.

State AOT Laws Required as a Condition of Block Grants. As discussed, AOT Laws give treating doctors and hospitals a middle path between commitment and release, and have been successful in other states. Maine passed one over DRC Maine's objections. HR 3717 would require states to enact AOT Laws. This is a much needed reform.

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[2] *Lawyers Who Break the Law*, at 153-54.

The Medical Records of William Bruce Show That DRC Maine Caused His Release.

By March 2006, Will had a well-documented history of dangerousness, paranoid thinking, and refusal to take medication. Amy and I repeatedly told his doctors of our fears for his safety and ours. We pleaded that he remain in an environment where he would be compelled to take the medications that were so effective in relieving his condition, because in an unmedicated state he lacked the insight to know he needed them. Unknown to us at the time, *because we were excluded from the meetings concerning his treatment*, the patient advocates from DRC were persistently and single-mindedly lobbying Will's doctors to release him from Riverview Psychiatric Hospital while simultaneously advising him he had the right to refuse medication. His mere *release*, not his successful treatment and our welfare as a family, was apparently their only goal. As a result of their interference in his treatment and their "advocacy" on his behalf, William was discharged from Riverview Psychiatric Center on April 20, 2006. Knowing DRC would defend his 'right' to refuse treatment, he did refuse it, and in a psychotic, unmedicated state he killed his mother on June 20, 2006.

NDRN's "Talking Points" memo is written to leave a deliberately false impression that DRC had nothing to do with Will's early and inappropriate release from commitment in April 2006. But as I show below, DRC persistently lobbied for his release, ignoring his doctor's dire warnings that he was "very dangerous indeed for release to the community."

In this memo I quote NDRN's assertions in the "Talking Points" memo verbatim, and respond with content from his medical records.

> **NDRN Assertion:** ***"There continue to be assertions that the Disability Rights Center (DRC) of Maine caused Mr. Bruce's release. However, because the hospital had taken no action to legally recommit him, he was due to be discharged."***

Response: Will's medical records show that DRC did indeed cause his release. His doctors were consistent in saying he needed treatment including medication, but DRC was consistent in insisting he did not need medication, there was no basis for holding him, and he should be released. Amy and I were excluded from the meetings where DRC Maine was making these assertions by rigid HIPAA privacy restrictions *[HR 3717 would ease those privacy barriers so families of the most seriously ill could get the information they need to help ensure their loved ones are cared for.]* Eventually DRC Maine's "advocates" wore down Will's doctors and the hospital, and he was released, unmedicated and unimproved. Amy's and my pleas were disregarded. The following are some excerpts from Will's medical records.

> **February 6, 2006:** Will was admitted to Riverview Psychiatric Center for 90 days because of aberrant behavior. The initial nursing assessment states "poor impulse

control," "delusions," "agitation," "noncompliance with meds," "isolative," "guarded," "assaultive."[3]

February 14: "Dangerous to others if discharged to a less restrictive setting at this time."[4]

February 23: "[D]angerous to others without additional observation, and active attempts to treat him."[5]

March 1: "[D]angerous to others without additional observation and treatment."[6]

March 7: "[W]ithout such treatment [i.e., medication], he would remain dangerous to others if released to the community without treatment." Diagnosis of paranoid schizophrenia.[7]

March 14: "[W]ith the patient's poor insight into his mental illness and with a history of dangerousness in the context of his mental illness, the patient remains dangerous to others without treatment."[8]

March 17: Will "refuses to take meds," and he says, "There's a law that says I don't have to take meds." *[HR 3717 would prohibit PAIMI-funded advocates from interfering with the doctor's treatment recommendation, as they obviously did in Will's case.]*[9]

March 20: Dr. Fliesser's notes state that Will is "dangerous indeed for release to the community without pharmacotherapy and decrease in paranoid symptoms."[10]

March 23: Treatment meeting. Amy and I were excluded, as usual, but two DRC employees attended, its General Counsel, Helen Bailey, and a patient advocate, Patricia Callahan. Will's doctor's notes recite that he "repeatedly emphasized to the disability rights advocate my clinical opinion that the patient's paranoid psychosis is not likely to improve without pharmacotherapy." DRC refused to hear it and instead strongly pressed for his release. Bailey, a lawyer, even asked if a second opinion could be obtained, and then "verbalized concern that she reviewed the record and saw no documentation to support William having to remain at Riverview." Callahan actually suggested that

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[3] Initial Nursing Assessment signed by RN Cecelia Garret [Tab1]. (References to "Tab __" are to a compiled notebook of Will's medical records on file with me.)

[4] Progress Note signed by Jeffrey M. Fliesser, MD [Tab 4].

[5] Progress Note signed by Jeffrey M. Fliesser, MD [Tab 5].

[6] Progress Note signed by Jeffrey M. Fliesser, MD [Tab 6].

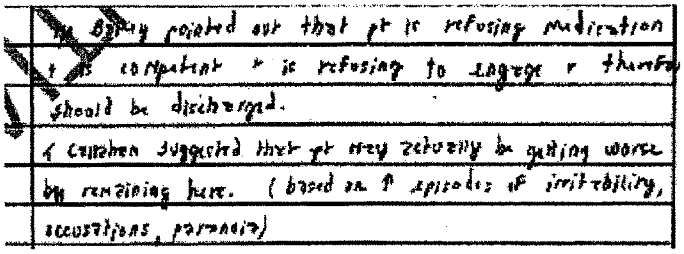
[7] Progress Note signed by Jeffrey M. Fliesser, MD [Tab 7].

[8] Progress Note signed by Jeffrey M. Fliesser, MD [Tab 10].

[9] RN Note signed by RN Valerie Files [Tab 11].

[10] Progress Note signed by Jeffrey M. Fliesser, MD [Tab 14].

William was getting worse by remaining at Riverview because his behavior was deteriorating while at Riverview.[11]



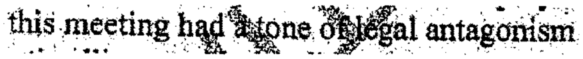
Ms Bailey pointed out that pt is refusing medication
& is competent & is refusing to engage & therefore
should be discharged.
& Callahan suggested that pt may actually be getting worse
by remaining here. (based on ↑ episodes of irritability,
accusations, paranoia)

March 27: Will "remains dangerous if released to the community without pharmacological treatment of these paranoid symptoms." Will continues to refuse medications, having been advised by DRC that he had a right to do so.[12]

March 30: Dr. William Nelson, medical director of Riverview, gives the "second opinion" sought by Bailey, and states "I agree [with Dr. Fliesser] that he is at high risk of being released to the community if he does not receive pharmacotherapy to ameliorate his paranoid and other psychotic symptoms."[13]

<u>[Dr. Fliesser leaves Riverview at this point; Dr. Filene takes over Will's treatment.]</u>

April 6: Dr. Filene describes Will's case as being "currently in a high state of contention." He meant that DRC Maine was continuing its campaign to secure his release without further treatment. At a treatment meeting on this date DRC's Callahan (1) told Will how to answer the doctor's questions, (2) told Will to refuse to consent to the doctor speaking to Will's prior treating professionals, and (3) told Will to refuse to consent to the doctor talking to Will's mother, Amy. (Callahan said *in Will's presence* that his parents – whom she had never met – were "a negative force in his life"! There is no knowing the extent to which the DRC's reckless statements about Amy and me contributed to Will's delusions that Amy had to be killed.) The doctor put in his notes the following:[14]



this meeting had a tone of legal antagonism

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[11] Progress Note signed by Jeffrey M. Fliesser, MD [Tab 15]; Progress Notes (unsigned) [Tab 16].

[12] Progress Note signed by Jeffrey M. Fliesser, MD [Tab 19].

[13] Progress Note signed by Jeffrey M. Fliesser, MD [Tab 21].

[14] Psychiatrist Progress Note signed by Daniel R. Filene, MD [Tab 23].

April 11: Dr. Filene meets with Will, who demonstrates that he views DRCs advocates as being at least co-equal in credibility to his doctor. Will justifies refusing treatment because of their advice and "continues to feel there is no reason to consider that he has an illness." The following excerpt from Dr. Filene's notes contain this information and more:[15]

Mr. B has difficulty understanding the difference in roles and expertise between his physicians and his state-appointed Advocates. Mr. B notes that the Advocates are stating he [illegible] not ill, not a danger, and should be released. He feels these opinions have the same or more weight as those of mental health professionals, and therefore continues to feel there is no reason to consider that he has an illness. Mr. B continues adamant that he will not consider accepting medication under any circumstances. He still states that this is because his previous medications had made him drowsy. He stated he still would not consider medication even if it didn't make him drowsy.

[HR 3717 would prevent the advocates from interfering with the doctor's treatment over the objections of parents in this way.]

<u>NDRN Assertion</u>: ***"DRC reviewed the medical record and alerted the facility that it had not taken action to obtain the necessary legal documentation to hold Mr. Bruce beyond his already scheduled discharge date."***

<u>Response</u>: NDRN phrases this "talking point" to suggest that DRC was benignly alerting Riverview Psychiatric that it needed to do more in order to hold Will. The reality is that DRCwas relentless in its determination to secure Will's release regardless of his need for further treatment, as shown above. Amy and I knew nothing of their efforts and Amy paid the price of their reckless disregard of his condition and his need for treatment prior to release.

<u>NDRN Assertion</u>: ***"When a psychiatric facility takes no such action to recommit, or when there does not seem to be sufficient evidence to support recommitment, mental health advocates work with hospital social work staff to develop and implement a quality discharge plan including housing, employment, case management, counseling and other support services."***

<u>Response</u>: It would have been remarkable indeed were Riverview Psychiatric Hospital to have taken steps to commit Will in the face of DRC's persistent and forceful lobbying for his release. The hospital yielded to DRC's pressure to release Will.

NDRN claims they worked for a "quality discharge plan" but there is no evidence of that. NDRN implies that in Will's case his release included provisions for "housing, employment, case management, counseling and other support services." This is false.

- "*Employment*" – False. Will was released to "Jesse," a supposed friend in Connecticut. Will had convinced DRC Maine and Riverview that Jesse had employment for him, but this was simply false – a creation of Will's imagination

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[15] Psychiatrist Progress Note signed by Daniel R. Filene, MD [Tab 24].

- "*Housing*" – False. Will's friend Jesse in Connecticut, to whom Will was directed on release, was supposedly traveling but would return two weeks from Will's discharge date, so Will was given enough money to stay in a hotel, by himself, for two weeks until "Jesse's" return.

- "*Case management*" – False. Will was equipped with the phone number of Andy Davis and exhorted to check in. He didn't.

- "*Counseling*" – False. Counseling was not part of Will's "quality discharge plan."

- "*Other support services*" – False. None were provided.

After DRC obtained Will's release, he was put in a hotel in Skowhegan by himself, and then put on a bus to Connecticut with spending money so he could "get back on his feet," in the memorable words of his Intensive Case Manager. Within a few weeks Will showed up at his grandmother's home in Massachusetts appearing psychotic. Amy and I had to bring him home. Our pleas for treatment had been intentionally thwarted by DRC's single-minded determination to enforce his "right" to be free, and untreated.

Notably, NDRN's description of the "quality discharge plan" in Will's case fails to mention medication. This is the only truthful aspect of that assertion, because there was no provision for meds, nor could there be any expectation that he would stay on his meds, given DRC's counseling that he need not. Moreover, at the time, Maine had no Assisted Outpatient Treatment law (a/k/a Kendra's Law) that would have required him to stay on his meds or face a return to the hospital. *[HR 3717 would fund pilot AOT programs in states.]*

In summary,

- DRC counseled Will he could refuse antipsychotic medications.

- In the treatment meetings from which Amy and I were excluded, DRCinserted themselves in between Will and his family and between Will and his treating psychiatrist, impeding the trust and open communication that is so essential to effective treatment.

- DRC counseled Will to refuse the doctor consent to talk to his family, whom they stated *in front of Will* was "a negative influence in his life."

DRC pressed over and over for Will's premature release from the hospital despite repeated warnings from three physicians that without the medication *the advocates were counseling him to resist* he would be a danger to himself and his community.

Once he was remanded to Riverview by the Criminal Court and treated, with medication and otherwise, Will regained insight into his condition. He now knows what his advocates were blind to in 2006. In a *Wall Street Journal* article published in 2008, Will himself said the following: "There are times when people should be committed. Institutions can really help. Medicine can help. None of this would have happened if I had been medicated."[16]

Is the Bruce Case an Anomaly?

How would we ever know? It was lucky that in my son's case DRC's actions were well documented by Will's treating doctors, so that when I was able to obtain his medical records, the truth emerged. But that is not the norm. NDRN and the patient advocates operate in the secrecy created by HIPAA. NDRN has a pattern of making extravagant public claims that it has investigated and helped thousands of cases of abuse, and it describes particular incidents in florid detail, *but HIPAA prevents its claims from ever being tested against the records.* So we can never know for sure, but I will say this:

From everything I have observed in the years since 2006, Helen Bailey and Patricia Callahan are products of the NDRN mindset and the PAIMI system.[17] The NDRN and patient advocates consistently express – and their actions display – an ideology that all care should be "self-directed." But this means that people like Will, who lack the capacity to self-direct their own care, are left without care. The flaw in the NDRN philosophy is that it protects the right to remain psychotic and ignores policies that can free a person from its grip. According to a SAMHSA report, NDRN's DRC affiliates are currently working to *prevent* AOT legislation.[18] Those activities are evident in New York, California, Tennessee, Kentucky, Connecticut and other states.

The advocates' intervention in Will's treatment stems from an overzealous belief that any diminution of the rights of a single mentally ill person creates a slippery slope that endangers the rights of the entire American population. Thus, patient advocates want to "win" their cases all the time, whether it's in the best interests of the patient or not. To them, using intimidation to get a patient like Will released is cause for celebration, notwithstanding the wishes of the family members who know him best (and who are his primary caregiver) or the doctors who have professional expertise. When a patient gets released, to them it is a victory for "individual rights," plain and simple. Civil liberties are of course important to all of us, but taking the defense of patients' rights to these extremes doesn't allow the doctors and mental health workers the room they need to actually treat their patients.

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[16] "A Death in the Family," WALL ST. JOURNAL, Aug. 16, 2008.

[17] This mindset, as well as illegal activities by Protection and Advocacy, was well documented in *Lawyers Who Break the Law*.

[18] *Evaluation of the Protection and Advocacy for Individuals With Mental Illness (PAIMI) Program, Phase III: Evaluation Report*, SAMHSA, 2011. Summary and link to full report at http://mentalillnesspolicy.org/myths/paimifails2011samhsaevaluation.html. Full report available at http://store.samhsa.gov/shin/content/PEP12-EVALPAIMI/PEP12-EVALPAIMI.pdf

Neither DRC nor NDRN has ever acknowledged any fault or even expressed remorse for what happened. HR 3717 cannot bring Amy back but if enacted it will cure many of the ills of the current system that contributed to her death. For the sake of severely mentally ill people and their families across the country, please support this excellent legislation.

Respectfully submitted,

Robert (Joe) Bruce

THE WALL STREET JOURNAL.

A Mental-Health Overhaul

A Congressman produces a set of good ideas for a difficult problem.

Board Editorial
December 26, 2013

A year has passed since the Newtown massacre, and Americans this month marked the somber moment. The most fitting tribute Congress could pay the 26 victims would be to return in January to take up Pennsylvania Representative Tim Murphy's thoughtful overhaul of federal mental-health policies.

Severe mental illness is the common link among the recent mass shootings, and for decades the political class has ignored the systemic dysfunction in a mental-health system that fails the sickest. Getting to the root of this problem is hard, which is why Congress defaults either to spending more money or brawling over gun control.

Mr. Murphy, a psychologist, has spent the year since Sandy Hook studying the problem. His House Energy and Commerce Subcommittee on Oversight and Investigations has dug into federal policies, and his reform is aimed at helping the next Adam Lanza before he strikes.

The feds spend a stunning $125 billion a year on "mental health" via programs ranging from Medicaid to the Social Security Administration. Yet the Murphy committee discovered that most of this cash goes to vague and ineffective services rarely focused on treating the most serious illnesses—schizophrenia, bipolar disorder or severe depression. There is little interagency coordination, little government data collection on treatment outcomes, and no central effort to drive evidence-based care.

A prime example is the Substance Abuse and Mental Health Services Administration in the Department of Health and Human Services. SAMHSA every year pushes $460 million in block grants to community mental-health centers. The agency is a fan of "patient driven recovery," which allows the mentally ill to craft their own treatments and stresses "hope" and "empowerment." SAMHSA has little or no focus on medically driven care, and of its 537 full-time employees only two are physicians.

The Murphy bill would reorient all of this and create a new HHS assistant secretary for mental health and substance-abuse disorders who would lead federal mental-illness efforts. The secretary would have to be a medical professional and would be responsible for promoting the medically oriented models of care adopted by the National Institute of Mental Health, or NIMH.

An example: One NIMH project showed that identifying the first sign of psychosis in an individual, and immediately treating it with lower-dose medication, could prevent a patient from developing full-blown schizophrenia and allow a functioning life. These are the treatments that federal dollars need to be supporting.

The new assistant secretary would take over the grant process; community centers that want money will have to prove they are meeting evidence-based standards. The new position will also be responsible for collecting data on treatment outcomes and shifting federal efforts based on the results.

The Murphy bill also uses grant money to push states to modernize their mental-illness laws. Some 23 states still allow for involuntary commitment only if a mentally ill person is an imminent danger to himself or others. This standard is nearly impossible to meet, and even psychotics are often able to present a brief façade of normality. Many are unaware they're even ill and won't voluntarily get help.

Community mental-health centers would only receive grants if their state's commitment laws include a "need for treatment" standard, which gives families and physicians greater ability to get help for the mentally ill. Grants would also flow only to centers in the 44 states that have assisted-outpatient treatment laws, in which courts can require the mentally ill, as a condition of remaining in a community, to receive treatment. New York's Kendra's Law has been a model for how these outpatient treatment laws can help the most vulnerable and save lives.

The bill includes other pressing reforms, like removing the federal bias against hospital psychiatric care. Medicaid currently won't reimburse for psychiatric care in any hospital that has more than 16 psychiatric beds. This restriction has led to the dismantling of psychiatric hospitals, releasing the mentally ill to commit crimes and receive subpar treatment in jails. Seventy years ago the U.S. had 600,000 inpatient psychiatric beds for a country half its current population. Today it has 40,000.

A similar shortage of psychiatric professionals—especially for children—has meant the average time between a first episode of psychosis and initial treatment can be 110 weeks. The Murphy bill addresses this by advancing tools like tele-psychiatry, which links primary physicians in underserved areas to psychiatric professionals. Speaking of children, the law finally fixes the federal privacy law known as HIPAA, once again allowing mental-health professional and families to share information about loved ones.

The Murphy legislation also addresses one of the more destructive forces in the mental-health system: the legal lobby. Many Americans may be shocked to know their tax dollars are funding a small army of self-anointed "advocates" who encourage the mentally ill to avoid treatment, and who fight parental and court attempts to get them care. The Murphy bill stops this funding. It also gives physicians legal safe harbor to volunteer at understaffed mental-health centers, something many currently won't do for fear of malpractice suits.

These provisions may inspire the opposition of some Democrats beholden to the trial bar and ACLU. The Obama Administration may also resist a GOP initiative, and libertarians may oppose giving professionals more authority to intervene with care or object to creating a new government position.

They should think anew. The alternative is Vice President Joe Biden's proposal to throw another $100 million willy-nilly at a failed system. All the money in the world won't help the mentally ill if it isn't getting to them or is squandered on ineffective treatments. The Murphy bill is an informed attempt to overhaul a broken system. It might even prevent the next Newtown.

Tim Murphy
U.S. Congressman for the 18th District of Pennsylvania

The Philadelphia Inquirer

OP-ED: Overhaul of mental health care long overdue

By: Rep. Tim Murphy
January 26, 2014

Over the last year, as chairman of the House Energy and Commerce Subcommittee on Oversight and Investigations, I embarked on a detailed review of the nation's mental-health system. With my 30-plus years' experience as a clinical psychologist, I was profoundly shocked to learn just how archaic and ineffective federal mental-health policy is in our country.

Easily two million patients with serious and persistent mental illness, many of whom lack insight into their schizophrenia or bipolar disorder, go without medical treatment. Why? Because the federal government has never approached serious mental illness as a health-care issue. This laissez-faire approach to brain illness has directly resulted in growing rates of homelessness and incarceration for the mentally ill over the last 20 years. Sadly, it has also led to numerous tragedies, including 38,000 annual suicides.

The result of my comprehensive review is legislation I introduced last month titled the Helping Families in Mental Health Crisis Act. This bipartisan legislation marks the most significant overhaul of the nation's mental-health system since President John F. Kennedy established community mental-health centers 51 years ago. It refocuses programs and resources on psychiatric care for patients and families most in need of services but who are currently the least likely to get it. My bill increases treatment options, integrates mental and physical care, and reduces barriers and the stigma associated with mental illness.

During my investigation, one barrier repeatedly showed up for families trying to help a loved one with a serious mental illness: Families and caregivers often are unable to share vital information with a physician about a loved one's medical history because of the consistent misinterpretation of the privacy rule under the Health Insurance Portability and Accountability Act (HIPAA).

My legislation strengthens HIPAA by empowering parents to talk about and receive information about a mentally ill loved one, which will allow physicians to make an accurate diagnosis.

Clarifying HIPAA rules is only the beginning of changing the paradigm so those with serious mental illness are treated with dignity and compassion. The legislation also encourages states such as Pennsylvania to adopt "assisted outpatient treatment" (AOT) laws, which ensure that mental-health providers target care and resources to the subset of seriously mentally ill who have repeat visits to the hospital emergency room. New York state's AOT statute, known as "Kendra's

Law," has reduced incarceration, emergency-room visits, homelessness, and substance abuse by about 70 percent among the mentally ill.

The current approach to mental health can best be described by its deficits: too little integration with primary or physical care; too few psychiatric hospital beds; too few psychiatrists, psychologists, and clinical social workers, especially ones who are trained and specialize in treating the seriously mentally ill.

The Helping Families in Mental Health Crisis Act promotes integration of mental health with the rest of the medical system. It also expands the number of pediatricians and primary-care doctors trained in behavioral health so children and young adults get immediate attention.

The inability to find qualified medical help deepens the severity of damage to the human brain, making recovery all the more difficult. Currently, patients wait on average two years after the first signs of psychosis before seeing a doctor. A breakthrough treatment project at the National Institute of Mental Health and the University of Pennsylvania, called Recovery After Initial Schizophrenia Episode, or RAISE, has shown tremendous results by treating the patient earlier with wrap-around services and low-dose medication.

Unfortunately, successful medical models such as RAISE are not getting out into the broader community. The Helping Families in Mental Crisis Act places a new emphasis on evidence-based models of care by establishing an assistant secretary for mental-health and substance-use disorders, who must have clinical and research experience in treating mental illness. This individual will ensure federal tax dollars are spent on effective programs and treatments. The legislation also authorizes the Brain Research through Advancing Innovative Neurotechnologies (BRAIN) Initiative, which was first called for by President Obama. The initiative will revolutionize our understanding of the human brain by producing a new dynamic picture of it that, for the first time, shows how individual cells and complex neural circuits interact in both time and space.

For far too long, those who need help have been getting it the least, and where there is no help, there is no hope. We can, must, and will take mental illness out of the shadows of ignorance, despair, and neglect and into that bright light of hope. It starts with the Helping Families in Mental Health Crisis Act.

Published on January 26, 2014.

Defending Liberty
Pursuing Justice

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March 31, 2014

The Honorable Joe Pitts
Chairman
Committee on Energy and Commerce
Subcommittee on Health
U.S. House of Representatives
2125 Rayburn House Office Building
Washington, DC 20515

The Honorable Frank Pallone, Jr.
Ranking Member
Committee on Energy and Commerce
Subcommittee on Health
U.S. House of Representatives
2415 Rayburn House Office Building
Washington, DC 20515

Dear Chairman Pitts and Ranking Member Pallone:

On behalf of the American Bar Association (ABA), representing nearly 400,000 members, I write to express our opposition to portions of H.R. 3717, the *Helping Families in Mental Health Crisis Act of 2013*. The ABA specifically opposes certain provisions that cut authorized funding for the Protection and Advocacy for Individuals with Mental Illness Act (PAIMI) programs, as well as provisions that bar PAIMI programs from using funds to engage in systemic advocacy or to investigate and seek legal remedies outside of individual cases of abuse or neglect.

Through the PAIMI program, Protection and Advocacy agencies (P&As) in every state and territory are mandated to protect and advocate for the rights of individuals with mental illness and to investigate incidents of abuse and neglect of these individuals in all public and private facilities and in community settings. P&As also have the authority to provide legal representation and other advocacy services to people with severe mental disabilities in order to protect rights guaranteed by the U.S. Constitution and all federal and state laws.

H.R. 3717 would cut funding for the PAIMI program by 85 percent, reducing its budget from $36 million to $5 million. Such a drastic cut would leave the 57 state and territorial programs without vital funds that are used to protect and serve some of our most vulnerable citizens. Last year, under the federally funded PAIMI program, the P&As provided essential information and referral services for 35,500 individuals with mental illness and provided training for over 80,000 individuals, family members, mental health planners and social service professionals. A radical cut in funding, such as the one proposed in H.R. 3717, would eviscerate the P&As' ability to provide these crucial services to such a large number of individuals who clearly need those services.

The PAIMI program also provided critical legal services to over 15,000 individuals regarding issues such as inappropriate or excessive medication, lack of appropriate mental health treatment, financial exploitation, need for transportation to or from residential care facilities, admission to residential care facilities, discharge planning, housing and employment discrimination, and denial of visitors. These examples of systemic advocacy and litigation, in which PAIMI programs engage on behalf of groups of individuals with serious mental illness, would be prohibited under H.R. 3717. The ABA opposes legislation that denies access to judicial remedies for persons in certain segments of the population – especially for those who are most at risk.

The consequences of these proposed restrictions will be real. Last year, mental health advocates working through a PAIMI program in Arizona negotiated a settlement that opened the door to community services as an alternative to a state hospital. Similarly, Disability Rights of Washington, a PAIMI agency, joined others in filing a class action lawsuit to compel intensive, individualized mental health services to Medicaid-eligible young people in their communities. In that case, the court approved an agreement that allowed for additional treatment of children at home, rather than in psychiatric facilities. These examples of life-changing interventions achieved last year through PAIMI programs would be curtailed under H.R. 3717.

As a result of PAIMI programs, tens of thousands of children have received the services that they need to gain full and equal access to education, health care, independent living, and employment. The ABA adopted policy in 2010 urging Congress "to provide adequate funding for the Protection and Advocacy system and related programs, and to preserve its authority to protect, represent, and fully investigate on behalf of persons with disabilities in institutions, facilities and the community." The provisions in H.R. 3717 that would cut and restrict the use of PAIMI funds clearly contradict those recommendations. We urge you to oppose the portions of H.R. 3717 that would diminish the PAIMI program's ability to provide these essential benefits.

Sincerely,

Thomas M. Susman

Thomas M. Susman

Submitted Testimony of the National Disability Rights Network On a Legislative Hearing on H.R. 3717 The Helping Families in Mental Health Crisis Act.

April 3, 2014

Thank you for the opportunity to submit written testimony for today's hearing to describe our concerns with H.R. 3717, the Helping Families in Mental Health Crisis Act of 2013, introduced by Representative Tim Murphy (R-PA). First, we recognize the importance of Congress taking a look at our nation's mental health system and performing rigorous and efficient oversight to ensure that the system is meeting the needs of individuals with all types of mental health disabilities, including those with the most significant disabilities. As both an economic and civil rights issue, the United States Congress should work to ensure a well-functioning mental health system in the United States.

Every day, the nationwide network of Protection and Advocacy (P&A) agencies in every state and territory (see http://www.ndrn.org/en/ndrn-member-agencies.html) learns from individuals, families, providers, and even policymakers of incidents of abuse, neglect, or civil rights violations concerning individuals with psychiatric disabilities. Last year, the P&As handled more than 15,000 individual cases and more than 35,000 information and referrals. These numbers show the need for Congressional attention to our nation's mental health system. The P&As are a nationwide network with deep connections to and understanding of the issues impacting people with mental illness, and as a result are best situated to respond at the local, state and national level and work collaboratively to address these issues.

While we appreciate the desire of Congress to focus its attention on this important topic, there are a number of provisions in H.R. 3717 that would need to be amended in order for the bill to have a positive impact on the nation's mental health system and improve the lives of persons with psychiatric disabilities. Without addressing the bill's issues, this legislation, taken as a whole, would compound the problems of our current mental health system, not solve them.

The following four provisions cause us the most concern.

First, H.R. 3717 proposes the elimination of initiatives such as evidence-based, peer-run services and family supports, which promote recovery from serious mental illness. These services have a proven track record in helping people stay out of the hospital and live successfully in the community. Eliminating these programs would lead to increased hospitalization, which is far more expensive and has far worse outcomes than these effective, and cost-efficient, community-based services.

This set of provisions would be a step backwards in mental health treatment. There is much evidence that peer-run services have a positive impact on people with psychiatric disabilities, and by restricting the ability to expend funds on these important programs, H.R. 3717 would ultimately hurt more people than it would help.

Second, H.R. 3717 would reduce and reorganize the Substance Abuse and Mental Health Services Administration (SAMHSA). SAMHSA does great work and funds important initiatives to address mental illness, including serious mental illness. While it is always useful to examine ways to increase the efficiency and effectiveness of a large agency like SAMHSA, H.R. 3717 would add another layer of bureaucracy and significantly cut funding that supports these initiatives. These changes would only make the mental health system in the United States weaker, not stronger.

Third, H.R. 3717 would enact a huge reduction in funding and impose severe restrictions on the Protection and Advocacy for Individuals with Mental Illness (PAIMI) program. This would eliminate most of the important work that Protection & Advocacy agencies do every day to protect individuals with mental illness from abuse, neglect and civil rights violations and help those individuals and their families to access needed mental health services and supports. The proposed 85% reduction in funding will also mean the loss of hundreds of jobs across the country, since this funding is primarily used by the agencies to employ attorneys and advocates who provide a continuum of legally-based advocacy services in every state and territory.

There is no benefit to gutting the PAIMI program, which was signed into law by President Reagan following an extensive Congressional investigation on the need for independent advocacy for individuals with psychiatric disabilities. The PAIMI program has successfully worked for almost 30 years to obtain services and supports and protect the civil rights of millions of people with mental illness. In 2013 and 2014, the PAIMI network won important systemic cases that helped thousands of people with psychiatric disabilities receive the necessary services and supports for them to receive an education, live in their communities, and become employed as tax-paying citizens. The destruction of the PAIMI program would only harm people with mental illness, their families, and our entire society

An example of a positive change that would be impossible if this bill were to become law involved a settlement recently obtained by Disability Rights Washington to ensure that more intensive, individualized mental health services to Medicaid-eligible young people in their homes or communities be developed, funded, and provided. Without this settlement, many youth in Washington would still not have access to the mental health services they need to remain in the community and successfully complete their education.

In another example, the Arizona Center for Disability Law reached a settlement to help increase services for people with seriously mental illness in Arizona. Thanks to this settlement, services including everything from medications to housing and supportive employment will now be more readily available to these individuals. Governor Brewer credited the mental health advocates, including the P&A, with providing "the hammer" to ensure the state lives up to its legal obligations.

A settlement by Disability Rights New York helped ensure that people with psychiatric disabilities receive needed services and supports in the most integrated setting. This will allow people to move them out of poorly managed board and care homes into better community options which will further their recovery.

In Ohio, a veteran was facing employment discrimination from an employer who refused to allow him to bring his support animal to work and also having problems getting needed services and supports from the Veterans Administration (VA). Disability Rights Ohio worked with the employer and the VA to get this veteran the services and supports he needed as well as educate the employer on the right to be accompanied by a service animal. Now this veteran is getting the services and supports he needs, and continues to be a tax-paying citizen at a job he enjoys.

This is just a small sampling of the examples of the important work that is done every day by P&As through the PAIMI program to help people with psychiatric disabilities, their families, and society. All of the proceeding work would cease if H.R. 3717 became law.

Finally, H.R. 3717 requires states to enact Involuntary Outpatient Commitment (IOC) (sometimes called Assisted Outpatient Treatment (AOT)) laws to be eligible for funds from the Mental Health Block Grant. Studies have consistently shown IOC requires a substantial commitment of treatment resources to be effective. See Swartz, M., Swanson, J., Wagner, H., Burns, B., Hiday, V., and Borum, R, "Can Involuntary Outpatient Commitment Reduce Hospital Recidivism?: Findings From a Randomized Trial With Severely Mentally Ill Individuals,"_AMERICAN JOURNAL OF PSYCHIATRY. 156(12): 1968-1975 (Dec. 1999). Lacking this commitment to increase treatment resources, H.R. 3717 requires states to adopt a policy that studies have shown will fail.

Although work needs to be done to repair the nation's mental health system, taken as a whole, H.R. 3717 would cause more harm to the people it purports to serve. We agree that improvements need to occur in our nation's mental health system to serve the people with mental health conditions, and would welcome the opportunity to work with the subcommittee to craft legislation that will move our nation's mental health system forward.

Testimony submitted for the April 3, 2014 Legislative Hearing on the"Helping Families in Crisis" Act of 2013 (H.R. 3717)

by the National Coalition for Mental Health Recovery

The National Coalition for Mental Health Recovery is an organization of people in recovery from serious mental illnesses. Our Coalition, with member organizations in more than 30 states, is a national voice of people who have been most severely affected by mental illness. We want to make sure our voice is heard and understood in Washington on the decisions that affect our lives and health, and in particular on HR 3717.

We agree with Representative Tim Murphy, the sponsor of HR 3717, that the current mental health system is inadequate to fully meet the needs of persons with psychiatric disabilities. However, HR 3717 will have serious unintended consequences. It would do away with many significant advances made in mental health care in the last 30 years and place federal and state governments at high risk for litigation under the Americans with Disabilities Act and the Supreme Court's *Olmstead* decision. No other population of persons with disabilities is subject to the civil rights violations that will be implemented by the provisions of this bill. Furthermore, the criteria proposed for coercing people into treatment, especially mandated medication usage, will usher in a new level of government intrusion into people's lives. Finally, HR 3717 disregards the body of research that clearly documents the negative impacts of forced treatment on long-term outcomes.

The bill's provisions, if adopted, would lead to increased discrimination and stigma against people with psychiatric disabilities. This is based on a fallacious belief that people with psychiatric disabilities are more prone to violence than other populations. This belief is not borne out by a significant body of evidence showing that they are more often victims of violence, not perpetrators.

1. This proposed legislation eliminates many hopeful, innovative initiatives that are already shown to promote recovery from mental health problems through the use of evidence-based, voluntary, peer-run programs and family services and supports. Dr. Daniel Fisher, Ph.D., M.D. states: "These services have a proven track record in helping people stay out of the hospital and live successfully in the community. Because hospitalization is far more expensive and has far worse outcomes than community-based services, this bill would cost more money for worse outcomes." Provisions that arbitrarily cap funding of SAMHSA Programs of Regional and National Significance and terminate all programs not specifically authorized in statute should be eliminated.

2. The bill attacks the Substance and Mental Health Services Administration (SAMHSA), the only federal agency which has adopted the recovery model. SAMHSA's alignment with recovery-oriented, community-based approaches

is rooted in a growing evidence base indicating that recovery approaches lead to better long-term outcomes for individuals with psychiatric disabilities and their families. Recent studies supported by the Foundation for Excellence in Mental Health Care and other funders are showing definitively that hope is a reasonable expectation for people with even the most significant psychiatric disabilities, such as people diagnosed with schizophrenia. These studies (Harrow, Wunderink, Harding, et al) can be provided at the request of any legislator or committee.

3. The bill proposes to essentially eliminate SAMHSA as it currently exists and institute yet another federal bureaucracy with yet another Assistant Secretary and Department. This proposition is wasteful of taxpayer dollars. The best way to reduce costs and to lower rates of disability is to advance initiatives and programs that promote recovery and wellness, which are already among SAMHSA's strategic priorities.

4. Key provisions of this proposed legislation violate *Olmstead v. L.C.* (1999) which requires treatment services to be delivered in the "least restrictive environment." Many states are already reeling from costly challenges to their current systems of care, and this will only increase the burden of both state and federal governments. The US Supreme Court has clearly laid the legal foundation to move away from institutional and coercive care, and people with disabilities deserve better than warehousing.

5. Research and field experience strongly indicates that when people know or believe they are going to be subject to coercive treatments, they will become even more resistant and try to avoid services as much as possible. These interventions are largely experienced as humililating, dehumanizing, and traumatizing to people with psychiatric disabilities. Provisions promoting court-ordered treatment will result in the exact opposite of the intentions of the bill.

   We reject provisions of this bill to elevate into Federal policy the criteria for involuntary psychiatric commitment and to withhold formulaic mental health block grant funds from states unless they change commitment criteria in their own state laws.

   We reject provisions throughout this bill that fund and promote use of involuntary outpatient commitment (IOC). Federal mental health policy should incentivize timely voluntary services and supports in the community that prevent crisis and deterioration and promote recovery. Involuntary outpatient commitment unnecessarily criminalizes people in crisis as a condition of receiving intensive services they needed to receive far sooner to avert crisis. It imposed additional coercion and trauma as a condition of receiving help, and drives people from services. It is costly, controversial and is not an evidence-based practice.

6. Finally, this bill would eviscerate the rights and privacy protections for people with mental illness, enshrined in the federally mandated Protection and Advocacy (P&A) System, which is the largest provider of legal advocacy services to people with disabilities in the United States. The bill singles out one group of people with disabilities, denies access to protection and advocacy, and compromises their rights. At a time when people with psychiatric disabilities are most likely to be misunderstood so that their American civil rights are violated, HB 3717 will create a huge litigation burden on federal and state governments. Most importantly, the dissolution of civil rights protections will threaten the hope and well-being of people and families struggling to regain their lives.

Provisions of specific concern include:

Section 102 – inter-agency serious mental illness coordinating committee: the bill would require nine non-federal members, including one individual who lives with a serious mental illness and one family member. Nonfederal members must also include a psychiatrist, a psychologist, a law enforcement officer, a judge with experience in assisted outpatient treatment, and a correctional officer.
Modification: There should be at least two persons with psychiatric disabilities and two family members among the committee members.

Section 1151 – SAMHSA may only finance programs that rely on evidence-based practices (EBPs).
Modifications: In addition to EBPs, there need to be provisions for funding innovative programs that further the vision of the New Freedom Commission and Institute of Medicine (IOM) report of 2006. Treatment and policy formation should be guided by the goals of recovery and continued self-determination of people with psychiatric disabilities and their families.

Section 1152 – SAMHSA may not finance any project that is not explicitly authorized by statute.
Modification: This provision should be dropped, as it also would eliminate any of the innovative programs developed by persons with disabilities and their families since the original authorization of SAMHSA.

Section 1102 – SAMHSA advisory councils must have at least 50% members who have a medical degree, an equivalent doctoral degree in psychology, or are licensed mental health professionals.
Modification: SAMHSA advisory councils should continue to reflect a collaborative approach, including licensed mental health professionals, certified peer specialists, persons with disabilities, and their families.

Section 1103 - requires that any SAMHSA review panel have at least 50% members who have a medical degree, an equivalent doctoral degree in psychology, or licensed mental health professionals.

Modification: This section should be reworded to say that any SAMHSA review panel should demonstrate expertise in the subject matter of the grant or contract under consideration.

Section 1112 - requires all proposed projects of regional or national significance to be submitted for prior review by House and Senate committees.
Modification: This would be burdensome and the subject matter is outside the expertise of House and Senate Committees; thus the provision should be dropped.

HB 3717 represents fear-based policy, and moves the United States in exactly the wrong direction. What people with disabilities, and their families, deserve are policies rooted in hope, recovery, wellness, and effectiveness. Increased resources for now well-researched early psychosis intervention programs, such as Finland's Open Dialogue, evidence-based prevention services, community and peer supports, would dramatically increase the availability of cost-effective, community-based services. We need to move forwards, not backwards, where HB 3717 would take us as a nation.

For more information contact Raymond Bridge, Director of Public Policy, NCMHR
Raymond.bridge@ncmhr.org 703-883-7710

CCD

**CONSORTIUM FOR CITIZENS
WITH DISABILITIES**

April 3, 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: <u>H.R. 3717, Helping Families in Mental Health Crisis Act</u>

Dear Representatives Upton, Waxman, Pitts and Pallone:

The Consortium for Citizens with Disabilities (CCD) Rights Task Force would like to submit for the record of the April 3, 2014 hearing on H.R. 3717 the attached letter sent earlier by the Task Force.

Sincerely,

Jennifer Mathis

Curt Decker
National Disability Rights Network

Jennifer Mathis
Bazelon Center for Mental Health Law

A. K. Finucane

Sandy Finucane
Epilepsy Foundation

Mark Richert
American Foundation for the Blind

Co-Chairs, CCD Rights Task Force

CCD
CONSORTIUM FOR CITIZENS
WITH DISABILITIES

Commemorating 40 Years
Of Disability Advocacy
1973-2013

January 28, 2014

Dear Representative:

The undersigned members of the Consortium of Citizens with Disabilities (CCD) Rights Task Force urge you not to cosponsor or vote for the Helping Families in Mental Health Crisis Act (H.R. 3717). CCD is a coalition of national disability-related organizations working together to advocate for national public policy that ensures full equality, self-determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society.

While this bill purports to aid families of individuals with serious mental health conditions, it actually contains numerous provisions that would *eliminate* significant and necessary protections for these individuals. For example, the bill would dramatically reduce the primary legal advocacy protection program for individuals with serious mental health conditions. It would also strip away important privacy protections from these individuals, and would eliminate federal funding for innovative community services and instead promote involuntary outpatient commitment, which undermines individuals' trust of mental health services and has little evidence supporting its effectiveness.

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

The bill would gut the primary system of legal advocacy protection for individuals with serious mental health conditions, the Protection and Advocacy for Individuals with Mental Illness (PAIMI) program leaving them without means to enforce their legal protections from discrimination in key areas of life such as education, employment, housing, health care, community living, voting, and family rights. The PAIMI program has been a leading driver of improvements in mental health service systems for the last several decades. As a result of this program, tens of thousands of children and adults have secured better lives, receiving the services they need to succeed in school, obtaining the chance to live successfully in their own homes, becoming or retaining employment, and receiving needed health and mental health care.

Yet this bill would cut funding for the PAIMI program by 85%, prevent the program from engaging in systemic advocacy on behalf of people with serious mental health conditions, and prevent the program from conducting advocacy on virtually all issues (including investigating reports of deaths) except for individual cases of abuse and neglect. These changes are neither fiscally sound, nor ones that protect the rights of this group. It is hard to imagine a more detrimental decision for individuals with serious mental health conditions.

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. Ironically, it is people with psychiatric disabilities who are often most in need of privacy protections due to widespread prejudices and stereotypes.

The bill would redirect federal money from innovative programs to involuntary outpatient commitment, which is expensive and ineffective

The bill would prohibit 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, an ineffective 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.

The bill would increase needless institutionalization

The bill would fundamentally change the Medicaid program by allowing states to obtain federal Medicaid reimbursement for inpatient psychiatric hospital services for non-elderly adults. These services have been the responsibility of states since the beginning of the Medicaid program almost fifty years ago. The exclusion of federal funds for these services has been an important means of promoting community integration. Federal reimbursement for these services would result in large numbers of individuals with psychiatric disabilities being served needlessly in hospitals, driving mental health systems backward.

We urge you not to cosponsor this legislation, and to vote against it. Please feel free to contact Jennifer Mathis, Bazelon Center for Mental Health Law, (202) 467-5730 ext. 313, or Eric Buehlmann, National Disability Rights Network, (202) 408-9514, with any questions.

Respectfully submitted,

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The Arc of the United States
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Association of University Centers for Excellence in Disabilities
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Silver Spring, MD 20910

Autistic Self Advocacy Network
PO Box 66122
Washington, DC 20035

Bazelon Center for Mental Health Law
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Community Legal Services, Inc. (Philadelphia)
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Philadelphia, PA 19102-2505

Disability Rights Education & Defense Fund
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Berkeley, CA 94703

Disability Rights Legal Center
Loyola Law School Public Interest Law Center
800 South Figueroa Street, Suite 1120
Los Angeles, CA 90017

Easter Seals
1425 K Street NW #200
Washington, DC 20005

National Council on Independent Living
2013 H St. NW, 6th Floor
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National Disability Rights Network
900 Second Street NE, Suite 211
Washington, DC 20002

Quality Trust for Individuals with Disabilities*

5335 Wisconsin Avenue NW
Suite 825
Washington, DC 20015

*In process of becoming a member of the CCD Rights Task Force.

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

Hon. Fred Upton
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Hon. Joe Pitts
Chair, Subcommittee on Health
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Hon. Frank Pallone
Ranking Member, Subcommittee on Health
237 Cannon House Office Bldg.
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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
President and CEO

FRED UPTON, MICHIGAN
CHAIRMAN

HENRY A. WAXMAN, CALIFORNIA
RANKING MEMBER

ONE HUNDRED THIRTEENTH CONGRESS
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April 22, 2014

Dr. David L. Shern
Interim President and CEO
Mental Health America
2000 N. Beauregard Street, 6th Floor
Alexandria, VA 22311

Dear Dr. Shern:

Thank you for appearing before the Subcommittee on Health on Thursday, April 3, 2014, to testify at the hearing entitled "Helping Families in Mental Health Crisis Act of 2013."

Pursuant to the Rules of the Committee on Energy and Commerce, the hearing record remains open for ten business days to permit Members to submit additional questions for the record, which are attached. The format of your responses to these questions should be as follows: (1) the name of the Member whose question you are addressing, (2) the complete text of the question you are addressing in bold, and (3) your response to that question in plain text.

To facilitate the printing of the hearing record, please respond to these questions with a transmittal letter by the close of business on Tuesday, May 6, 2014. Your responses should be mailed to Sydne Harwick, Legislative Clerk, Committee on Energy and Commerce, 2125 Rayburn House Office Building, Washington, D.C. 20515 and e-mailed in Word format to **Sydne.Harwick@mail.house.gov.**

Thank you again for your time and effort preparing and delivering testimony before the Subcommittee.

Sincerely,

Joseph R. Pitts

Joseph R. Pitts
Chairman
Subcommittee on Health

cc: The Honorable Frank Pallone, Jr., Ranking Member, Subcommittee on Health

Attachment

MHA
Mental Health America

May 5, 2014

Sydne Harwick
Legislative Cleark
Committee on Energy and Commerce
2125 Rayburn House Office Building
Washington, DC 20515

The Honorable Joseph R. Pitts

Question 1

> **How much in federal dollars did Mental Health America (MHA) and its affiliates receive over the past three years (in the form of grants, cooperative agreements, contracts, etc.)? Which federal agencies administered this funding and under what statutory authorities? In each of the past three years, what fraction of MHA's—and approximately what fraction of its affiliates'—annual budgets did such federal funding constitute?**

Because Mental Health America (MHA) affiliates are separately incorporated entities, we can't provide a definitive answer to this question. We ask individual affiliates to identify the percent of the budget that comes from government grants or contracts, but we do not ask them to break this down by federal or state, county, or city amounts. In addition, some states have elected a structure of affiliation where only the state offices affiliates directly with our national office, and local affiliates do not provide this information directly to the national office. MHA affiliates are listed on our website.

Each year, we summarize publicly available versions of affiliate tax returns (990s) and consolidate that information. We usually separate government support (which includes federal, state, and local grants, contracts or cooperative agreements) and program service revenue (which includes both federal reimbursements for services as well as revenue generated from certifications, conferences and non-federal program service revenue). There is no way for us to differentiate which program service revenue comes from the federal government versus what is generated by the affiliate from other sources, nor is there a way for us to identify what government grants come from the federal government and which come from state or other local governments.

Over the past 3 years, we have recorded, for the field (data lag by 1-2 years):

	2012	**2011**	**2010**
Government Grants	125,831,547	124,925,361	125,626,144
Program Service Revenue	77,144,894	78,294,773	102,506,241
Total Revenue	243,684,603	246,606,014	278,695,326

Given that the vast majority of the work that the affiliates do is at the state level, we estimate that the vast majority of the government grants come from state and local governments.

For the national office of Mental Health America, over the past 3 years we have recorded:

	2013	2012	2011
Government Grants	319,673	0	0
Government Contracts	106,864	309,336	689,441
Total Government Revenue	426,537	309,336	689,441
Total Revenue	3,014,703	2,651,887	3,758,958
% of Total Budget	**14%**	**12%**	**18%**

We are more often subcontractors than prime contractors on government contracts.
Agencies included:

SAMHSA

- HHSS280200900006C – SAM116059
- HHSS283200700029I/HHSS28342002T
- HHSS283200700020I, Task Order HHS28342002T
- HHSS28320070008I, Task Order HHSS28342002T
- HHSS283200700020I, Task Order HHSS28300001T, Reference 283-07-2001
- HHSS283200700020I, Task Order HHSS28342003T

SAMHSA/HRSA

- 1UR1SMO60319-01

NIH

- P20MH078188-04, Project 1008680; Task 4; Award 25017, CFDA #93.242

CMS

- PPHF – NAVCA130045-01, 93.750

Question 2

> **In your tesitmony, you state that "the wholesale abandonment of the PAIMI funtion would be disastrous in our current systems." Is there any provision of H.R. 3717 that envisions and/or mandates a "wholesale abandonment" of the original mission of the system established under the Protection and Advocacy for Individuals with Mental Illness Act of 1986?**

H.R. 3717 (under Section 117: Authorization of Appropriations) proposes $5 million for each of the fiscal years 2014 through 2017 for Protection and Advocacy. Currently the appropriation is $35 million. This is an eighty-five percent reduction. We interpreted an 85% reduction in funding to indicate a wholesale abandonment of Protection and Advocacy since it would effectively render the P&As unable to fulfill their mission.

Continuing problems with the public mental health systems require effective protection and advocacy services. For example, on May 1, 2014[i] Connecticut settled a law suit which began eight years ago, which was jointly filed by its state Protection and Advocacy program and the Bazelon Center for Mental Health Law, that ended the practice of housing hundreds of people with mental illnesses in nursing homes in violation of the American's With Disabilities Act. In settling this suit the State also addressed the issue of elderly patents residing alongside people of all ages with serious mental health conditions. The State has agreed to house people in the community and provide intensive wrap-around services for them.

In April the Disability Rights Law Center in Massachusetts (the state's Protection and Advocacy organization) began a new investigation of the Bridgewater State Hospital[ii] over allegations of abuse and neglect and the frequent use of seclusion and restraint for persons with severe mental illnesses. In 2007 the Disability Law Center sued and won concessions from this same institution over its excessive use of solitary confinement for those housed in its forensic unit. Also in April Kentucky's Protection and Advocacy agency advocated for the State to provide more appropriate oversight to a notorious group home that housed mentally ill men[iii]. The deplorable conditions that were revealed from the investigation included residents covered with insect bites, bare beds and filthy and broken plumbing. Without on-going support of Protection and Advocacy horrific abuses such as these would likely not be exposed or remediated.

Question 3

> **In your testimony, you state that "none of the research to date has estimated the number of persons who avoid any contact with the treatment system as a result of the potential coercion." You also assert that "our treatment systems should be welcoming rather than frightening." If, as you say, studies demonstrating the chilling effect of civil commitment laws on the seeking of treatment do not presently exist, on what basis do you oppose Assisted Outpatient Treatment as a tool for treating the seriously mentally ill when other research to date has shown its effectiveness?**

In the testimony, I was citing the research on Assisted Outpatient Treatment (Involuntary Outpatient Commitment) which has not estimated the degree to which these programs cause individuals with severe mental illnesses to avoid engagement in the treatment system. However, there are many studies that conclude that mandated treatment can cause individuals to avoid the treatment system. For example, a multi-site study done in Chicago, IL, Durham, NC, San Francisco, CA, Tampa, FL, and Worcester, MA demonstrated that for more than one-third of people across these sites coercion, or the fear of coercion, had a negative effect on treatment adherence, as well as damaging the therapeutic alliance between patient and clinician[iii]. This study and others like it found that the effects of coercion potentially outweigh any benefits which may have come from mandated treatment[iii].

A landmark study in California found that 47% of people with mental illness avoided seeking treatment for fear of involuntary commitment. The percentage of people avoiding treatment rose to more than half (55%) if they had previously been subject to involuntary commitment[iii].

Further studies that show benefits from mandated treatment, such those done on New York State's Kendra's Law, conclude that it is difficult to attribute positive outcomes for people subject to this law to being under court order rather than to having access to intensive services[iii]. Evidence indicates that coercion can stifle consumer engagement with ambiguous evidence regarding its benefits in accountable, engagement oriented systems.

Question 4

> **Dr. Tom Insel, Director of the National Institute of Mental Health (NIMH), informed the Subcommittee last year that treatment can reduce the risk of violent behavior 15-fold in persons with serious mental illness. In your testimony, you assert that "there is no simple link between mental illness and violence." Do you believe that, contrary to what Dr. Insel has told the Subcommittee, there is no simple link between untreated serious mental illness and violence?**

I don't interpret Dr. Insel's comments as indicating that a simple link between mental illness and violence exists. I interpret his comment as indicating that persons with severe mental illnesses who are effectively treated are less likely than persons who are not effectively treated or untreated to engage in violence. I have no quarrel with that conclusion. However, it doesn't address the full range of antecedents of violence.

One of the best analyses of the antecedents to violence was conducted by Swanson and his colleagues (Swanson, et al., 2002, American Journal of Public Health, Vol. 92, No. 9, 1523-1642) who demonstrated that the annual rate of violence among persons with severe mental illnesses in near zero if they do not have a substance use disorder, are not exposed to violence in their neighborhood or are not victims of violence themselves. However, as individuals accrue these other characteristics, the likelihood of some violent act increased to near 30% for persons who were victims of violence, used substances and lived in violence prone neighborhoods. Therefore, it is these additional characteristics that account for the likelihood of violence and not simply having a severe mental illness. Studies like Swanson's lead us to conclude that there is no simple relationship between mental illness and violence.

Question 5

> **In your testimony, you correcly state that H.R. 3717 "seeks to limit services supported by SAMHSA to those that have an evidence base." On March 9, 2009, President Obama released a memorandum for the heads of executive departments and agencies assigning to the Director of the Office of Science and Technology Policy "the responsibility for ensuring the highest level of integrity in all aspects of the executive branch's involvement with scientific and technological processess." Do you not agree that the activities SAMHSA, a component agency of the Public Health Service, should always be evidence-driven and based on scientifically rigorous research demonstrating their effectiveness?**

SAMHSA has many roles to play in the behavioral health system in the United States. Among these roles is support for the development of novel approaches to better serve the needs of persons with mental and addictive illnesses. In this latter role, it is essential that SAMHSA provide support for as yet untested interventions. However, it is also of critical importance that these innovative approaches be rigorously evaluated so that their key elements, effectiveness and implementation strategies be fully understood. To the degree to which they are proven to be effective, they will become the next generation of evidence based practices. Outside of innovative and rigorously evaluated programs, we believe that behavioral health treatment supported by SAMHSA or any other payer should conform to our best evidence and be delivered with high fidelity to the models that have been shown to work through systematic research.

The Honorable Michael C. Burgess

Question 1

> **Earlier this year CMS proposed rulemaking would have dramatically reduced coverage to critical medication used for treating mental health conditions, transplants, and other conditions. I understand that Mr. Murphy's legislation contains provisions that would prevent this from happening in the future. Will you discuss the importance of patients having access to and coverage of the most clinically appropriate pharmaceutical interventions?**

Given the idiosyncratic responses to psychiatric medications that characterize mental illnesses, we believe that access to a full set of medication options should be available to clinicians and their patients as they design treatment plans. We believe that informed consumers and clinicians can make the best decision about which medication work for whom and that arbitrary limitations are likely to ultimately increase costs owing to untoward side effects, decreases in treatment adherence and avoidable crises that may result in expensive and intrusive episodes of residential or hospital care.

Respectfully,
David L. Shern, Ph.D.
Senior Science Advisor
Mental Health America

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[i] Settlement Bars Placement of Mentally Ill in Nursing Homes: *Associated Press,* May 1, 2014: *The Connecticut Law Tribune* http://www.ctlawtribune.com/id=1202653539696/Settlement-Bars-Placement-Of-Mentally-Ill-In-Nursing-Homes?slreturn=20140402152745

[ii] New scrutiny for Bridgewater State Hospital after complaints, Boston Globe, April 17, 2014 http://www.bostonglobe.com/metro/2014/04/16/watchdog-group-for-disabled-launches-investigation-troubled-bridgewater-state-hospital/XN2edcSklgF3mMZ2G1p0NJ/story.html

[iii] Press Release—Kentucky Protection and Advocacy, April 29, 2014

[Dr. Welner's response to submitted questions for the record has been retained in committee files and can be found at *http://docs.house.gov/meetings/if/if14/20140403/102059/hhrg-113-if14-wstate-welnerm-20140403-sd002.pdf*.]

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