CAMPAIGN TO INSURE MENTAL HEALTH
AND ADDICTION EQUITY

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Elwyn Media Campus, Administration Building
Conference Room 317 (Third Floor)
111 Elywn Road
Elwyn, Pennsylvania 19063

Reporter: Christina Warner
United States Representatives:

Congressman Joe Sestak, Pennsylvania
Congressman Patrick Kennedy, Rhode Island

Panelists:

Joseph A. Rogers, President, Mental Health Assoc.
Estelle B. Richman, Secretary, Department of Public Welfare, Pennsylvania
Arthur C. Evans, PhD., Director, Philadelphia Department of Behavior Health and Mental Retardation Services, and Acting Commissioner, Philadelphia Department of Health and Human Services
Sandra Cornelius, PhD., President, Elwyn
Debra Plotnick
Ivy Silver
M. Theresa Landis
Allen McQuarrie, PRO-ACT (Pennsylvania Recovery Organization - Achieving Community Together)
Carol Caruso, Executive Director, NAMI Pennsylvania, Montgomery County
Alan J. Hartl, M.S., Executive Director, Lenape Valley Foundation, Inc., and Co-Chair, Pennsylvania Community Providers Association Legislative Affairs Committee
Kimberly Best, M.D., Department of Psychiatry, Albert Einstein Medical Center, on behalf of Pennsylvania Psychiatric Society
CONGRESS SESTAK: Thank you, and Sandy, thank you for hosting this. This is great. It's a real honor to be here today for me. We announced 2 February a year ago, for the campaign. I put up on my website, four papers. One on defense, one on health, one on education and one on the economy. I truly believe that National Security begins at home in the health, the education, the economic promise of our children.

Very few people looked at the nine steps that I had in my three page health paper. But one of them -- one of those steps was mental parity. I truly believe in it and I was touched, when Representative Kennedy approached me and asked if I would like to have him come up here on this tremendous Bill, that I think is going to move us far down the road.

I think this strikes at the heart of a significant issue in America, and that's of equal opportunity. I've watched and learned, in my time in the Military, and as I read history, that there are those moments where Americans look at the national mirror, at themselves, and say, "We are better than this."
We did it when we abolished slavery and kept the union together. We did it and we gave women the right to vote. I honestly believe this is very, very similar.

Mental health and physical health are inseparable. Why aren't they treated equally? Why are there artificial limits placed upon treatment for this disease?

I think that when you step back, it's like most other issues. If everyone contributes, everyone benefits. The estimates of the cost, the indirect cost of mental health, that are untreated -- mental health that is untreated is three times what it would cost, if we did directly invest in mental parity.

In my own recent career, I've watched as the Military comes home from Iraq. The estimates are that about 17 percent of them need some sort of attention in mental health, whether it's anxiety or depression or PTSD, and about 40 percent of those go untreated.

And so, to Congressman Kennedy, thanks a lot. I'm touched that you're here. I think it goes to the real saying about what Government is all about. Hubert Humphrey said it best, "The real test of a Government is how well it takes care of those in the
dawn of life, the children, those in the twilight of
life, the elderly, and those in the shadows of life,
the sick, the needy and the handicapped.

So, I think once again, due to efforts
from a lot of people in this room and led in the house
by Patrick Kennedy, I think we're about to say again
in that national mirror, "We are better than this."
So, thank you, and I'm honored to turn it over to
Congressman Patrick Kennedy.

(Applause)

CONGRESSMAN KENNEDY: Thank you very much,
Joe. I know my colleague, Jim Ramstad would love to
be here today and it's no indication of his lack of
interest to be here, that he isn't. I think I've
pretty much worn him down. He's been joining me with
all of these hearings across the country. We've been
at nearly two dozen over the last couple of weeks. We
just got back from the west coast, where we did
hearings in Oregon, Washington, California and
Colorado, and did multiple hearings in all of those
states, including several college campuses, where we
talked about suicide on college campuses, which
tragically, as many of you know, suicide is the third
leading killer of young people 15 to 24 in this
country, the third leading killer.
In fact, yesterday, we had a hearing in Trenton, New Jersey and a woman, speaking on behalf of a family, sort of suicide victims, presented us four three-ring binder books of obituaries, just in New Jersey, from the last 10 years of suicide victims. So, just obituaries of suicide victims in New Jersey, and when you consider the fact that 34,000+ people take their lives every year in this country, twice the number of people than are killed by homicide, it is a sobering thought, especially when you look at the picture of those young people's faces and read the obituaries and they say, "Died suddenly, died suddenly, died suddenly," and you see these young people's faces and you think to yourself, "How tragic is it that these people's lives are cut short," all because we in this country have refused to talk about it. We have refused to talk about it.

Silence is the biggest killer. Silence is deadly. But you know what? You've got somebody who is running against the grain. I will tell you, a stigma so powerful and there aren't but a handful of members that are really out there on this issue, really out there on this issue, and you can be proud that your member of Congress, Joe Sestak, who is a freshman who has just gotten into Congress, has...
already become one of those members, because of his credentials, his credentials being a leader in our Military and a civilian -- being such a respected leader -- his ability to speak on this issue, because frankly, ladies and gentlemen, this thing is so laden with stigma, that having a Three Star Admiral, you know, with his credentials, come out and say, "This is an important issue."

(Applause)

CONGRESSMAN KENNEDY: And say that this is a part of National Security, and that when the President of the United States talks about supporting our Troops, that he's going to make sure that it's not just empty rhetoric, because he has been there on the line with our Troops, and that he knows intimately, who are Troops are, because he served his lifetime with those Troops, and he's not about to let them be abandoned when they get back home, and that he wants to make sure that whey they get back home, they're not home only in body, but they're back home in mind and in spirit as well. That's Joe Sestak. That's the Congressman you can be proud to call your Congressman.

I'm proud that I have the opportunity to serve with him, and I know that in this Congress, with the support that he has, the leadership that is giving
to his cause, we're not only going to be able to fight for parity, but we're going to be able to fight for a broader agenda that restores a lot of money in our Veteran's budget for our Veterans, that is able to put a great deal of work into the SAMHSA Authorization, to break down those silos within and between mental health and drug addiction, so that there aren't those arbitrary silos in between the two, that addresses the issues that are in our corrections system, that make our corrections system, our mental health system of last resort, that address the many issues that are replete within our human service system, that create the fact that many of our young people get caught in, our foster care system, because there is no other way for them to get mental health treatment.

So, there are a lot of issues that we have to deal with, but I know with Joe Sestak working, we're going to be able to get a lot of these issues addressed. So, I look forward to hearing the testimony today. He absolutely hit it on the head. This is an issue of civil rights at its core and frankly, it is an issue of equal rights.

If people were treated equally, this would not be the case. This is a physical illness, and we know better. The brain scans tell us it's a physical
illness, but we refuse to treat it as such and as such, it is a discriminatory illness. And so, I think that that's why we have to work to pass parity, because it's an issue of civil rights as well.

So, I appreciate Sandra giving us the opportunity to be here. I thank you for the work that you do on behalf of the developmental disabled, as well. My family has always believed very powerfully that that work is very important, and I thank you for that, for the work that you've done, in that regard. So, I really appreciate your welcoming us and turn it over to you.

MS. RICHMAN: Thank you, Sandy. Thank you, Congressman Sestak, Congressman Kennedy, parents, consumers and health care advocates.

My name is Estelle Richman and I am the Secretary of the Department of Public Welfare for the Commonwealth of Pennsylvania. I welcome this opportunity to testify before the Committee.

Under the direction of Govern Edward Rendell, the Department of Public Welfare works closely with many partners in and out of Government to care for Pennsylvania's most vulnerable citizens. That includes children and adults living with mental illness, the very people most directly affected by the
issues we're going to talk about today.

I applaud your work in holding these public forums across the country. You have already heard a lot of testimony regarding the basic disparities between the way physical and behavioral health issues are treated by private health care plans.

Children and adults suffering from mental illness are routinely subject to higher deductibles, co-pays and co-insurance requirements. These individuals must also navigate arbitrary caps on visits in lifetime spending ceilings, as they pursue treatment and ultimately, recovery.

I would like to focus my remarks today on the important sub-group, mainly, children with special behavioral health needs.

In Pennsylvania there are tens of thousands of children struggling with conditions like attention deficit disorder, autism and other pervasive developmental disorders, learning disorders and organic milia disorders.

I don't know of anyone who would argue that these young people do not deserve access to afford, quality care. However, the current system of private health insurance fails these children by
treating physical health differently than behavioral health. Moreover, the current system has the undesirable consequence of shifting the cost of health care from private insurers to the tax payer.

As in most states, Pennsylvania provides Medicaid eligibility to people who qualify as disabled under the Federal Supplemental Security Income, or SSI statute. In Pennsylvania there is one important difference. In 1988, Pennsylvania made a policy change, so that children with disabilities could be made eligible for Medicaid, regardless of parental income.

In other words, eligibility for health care services is now based solely on the child's medical condition, not on the parent's finances.

These children qualify under Medicaid category PH-95, and they are sometimes referred to as "loophole children". There are about 37,000 children in this category today. One of the most compelling reasons to extend Medicaid eligibility to these children is that it helps keep families together.

In some cases, families lack private health insurance, but when they're too well off to qualify for Medicaid, found the only way they could insure their disabled child would have access to
medical care was to relinquish custody to the State. According to a recent nationwide study, at least 12,700 families released custody of their children to obtain state funded mental health services for their child in a single year. Many of them cited gaps in insurance coverage as a major factor in the decision to give up custody.

I am glad that today, Pennsylvania families have more options and that children with special behavioral health needs are more likely to get the care they deserve. However, I strongly believe that these families should not be forced into the public system and instead, should be able to purchase private health care coverage that meets both the physical and the behavioral health needs of their children.

This problem affects families in every part of the state. You may be surprised to learn that Delaware County has more families in this category than the City of Philadelphia. Forty percent of the special loophole families earn less than $40,000 per year and another 50 percent of families earn between $40,000 and $100,000. Roughly 10 percent earn more than $100,000, with the top one percent of families making over $250,000 annually. In other words, the
majority of these families are what most folks would
call middle-class.

Two out of three of the loophole families
have some type of private health insurance coverage.
The fact that such a large proportion of households
need to supplement private insurance coverage with
Medicaid, shows that the current system is not
working.

Nationwide, we know 87 percent of private
employer plans place no restrictions on mental health
coverage in comparison to medical or surgical care.
What is even more shocking than the statistic, is the
fact that these 87 percent are plans that actually
comply with the Federal Mental Health Parity Act of
1996. Two-thirds of these plans put lower caps on
out-patient visit and/or hospital days for behavioral
over physical health care, and one quarter impose
higher co-pays and/or co-insurance requirements.
These restrictions make it harder, if not impossible,
for children with special and behavioral health needs
to access care. In some cases, specific diagnosis may
be excluded all together, with serious consequences
for children.

A study by researchers at the University
of Pittsburgh looked at behavioral health plans
administered by large managed care organizations and
found that childhood diagnoses, including autism and
childhood psychosis, relational and abuse related
problems of impulse control disorders were frequently
excluded from coverage.

It is hard to imagine employer plans
imposing the equivalent kinds of exclusions for
childhood diseases or other physical health
conditions.

Consider the challenges faced by this real
life family living in Western Pennsylvania. The
father is a practicing attorney, with his own small
firm, where he has health insurance. His youngest
child, Peter, was diagnosed with autism when he was 18
months old. Within a few weeks, his son lost all his
language skills and also began to develop a chronic
sinus condition and many sensory issues.

Peter attends early special education and
receives speech and occupational therapy and now
started to regain his speech with a few words at time.
However, none of this service is covered through his
insurance. In fact, all services related to autism
are categorically excluded from the family's health
insurance coverage.

What is especially unfair is that Peter
had been suffering from some gastro-intestinal illness, prior to being diagnosed and all of his services, minus co-pays, were covered. After the autism diagnosis, reimbursement stopped. For this, the family pays an insurance premium of $2,700 per month.

This is not an isolated case. Many families -- many parents struggle, trying to find access to private insurance coverage for treatment of their children with autism or autism spectrum disorder. In Pennsylvania, the Autism Advocacy Group worked with a Harrisburg area insurance broker and determined that large insurers will not reconsider standard autism exclusions, unless it a company is very large.

This gap means that the vast majority of Pennsylvania employers cannot purchase appropriate coverage from any private insurance in Pennsylvania. One parent, who also works for an insurance company, expressed her frustration with the system saying, "I work for my insurer and I can't even get my son's services covered." It is us, as taxpayers, that must cover costs for these children.

We have analyzed fees for service and managed care claims data from fiscal year 2005/2006,
the last full fiscal year, and found that the Commonwealth spent a total of $411,000,000 on services for children in eligibility category PH-95. The state shared this total with about $176,000,000, with Federal share accounting for the other $235,000,000.

In reality, the financial split between the Federal and State Government dollars doesn't really make a difference. Either way, it is the taxpayer who ends up picking up the tab.

Clearly, there's a break down in our system. Hard working families can't purchase the coverage they need. Costs are shifted back to the taxpayers, and the most vulnerable citizens, children with special needs, risk receiving inadequate or no care at all.

More than half of children with a mental disorder, such as depression, bipolar anxiety disorder, do not receive the treatment and services they need and the results can be devastating.

Suicide is the leading cause of death among college students and the third leading cause of death among all youth 15 to 24 years old. Only accidents and homicide claim more lives, and we need to do better by our young people.

In this recent budget address, Govern
Rendell offered a sweeping prescription for Pennsylvania, to increase access to affordable health care coverage for all Pennsylvanians. I am pleased to say that as part of this comprehensive plan, the legislation would prohibit all health insurers from excluding minor children with behavioral health conditions from coverage, or excluding them from covered services, behavioral therapy services for minor children.

Covering behavioral health conditions differently than physical illness is fundamentally wrong and unfair. This is especially true for children. There is no reasonable justification for making it more difficult for a young child to receive treatment for autism, than their classmate to get her tonsils removed.

It has been over a decade since Congress passed the Federal Mental Health Parity Act of 1996. In that time, nearly two-thirds of the states have enacted Mental Health Parity laws, but that does not mean we are two-thirds of the way to equal treatment.

We need a stronger Federal law that will guarantee health plans in all 50 states offer fair coverage. I am strongly supportive of the efforts of the leaders of this forum. Thank you very much for
the opportunity to testify.

(Applause)

MR. EVANS: Good morning, Representative Sestak and Representative Kennedy. My name is Dr. Arthur Evans. I am the Director of the Philadelphia Department of Behavioral Health and Mental Retardation Services, as well as recently, the Acting Commissioner for the Department of Human Services, which is this city's Child Welfare Agency.

You probably have heard and you're probably going to hear a lot of very compelling stories, and you will probably hear that it's unfair to have a discrepancy between how physical health care and behavioral health care is addressed in insurance plans, and you will probably hear a lot of compelling stories about the issue of access.

I wanted to take just a few minutes to talk about a couple of things that you might not hear and emphasize a couple of things that I think are important, particularly as the leader of a large urban behavioral health care system.

The first is that, as you heard Secretary Estelle Richman allude to several times in her testimony, one of the primary reasons why you and I, as policy makers, have to be concerned about this
issue of parity is that there is a tremendous cost shift to the tax payer. It's a tremendous cost.

I work with Police Commissioner, Fire Commissioner, Health Commissioner, Prisons Commissioners, and I can guarantee you that if you ask any one of them, what are the one or two drivers of your budget, they will tell you, without question, it is untreated mental health and substance abuse disorders, unquestionably.

And so, when people don't get the care that they need through the private sector, it is as if my -- as my mechanic will say, "You can pay me now, or you can pay me later," and unfortunately, when we pay later, it is at a much greater cost than when people get the care that they need early on.

And so, one strong argument that -- for parity is that it is tremendously costly to -- not only to us as tax payers, but the human cost, when you think about the people who die from people who are -- who drive while intoxicated and other things, it is a tremendous cost to our society.

I want to jump ahead to -- and I'm going to assume that we're going to be successful with this effort to reach parity, and talk about a couple of things that I'd like for you to be thinking about,
hopefully, as parity comes through fruition, and that
is, as I look at the private sector, the private
sector plans versus the public sector plans, I can
tell you, if I had a behavioral health condition, I
would much rather be in the public sector.

This is an area where I think the public
sector can learn from the private sector. You
probably are aware of the President's New Freedom
Commission on mental health. You've probably heard of
the Institute of Medicine's, Crossing the Quality
Chasm Report, and there are a number of other reports
that have talked about where we ought to be going as a
system, as a field, in terms of the treatment of
mental health and substance abuse conditions.

One of the key ideas that came out of the
President's New Freedom Commission Report is the idea
of recovery, and long-term recovery, that we cannot
afford, certainly as a leader of a system, to continue
to fund only acute care services. That's the way our
health plans are set up, so you can get so many days
of hospitalization, you can get so many days of out-
patient.

But the reality is that substance abuse
conditions, mental health conditions are chronic
conditions and they require a different approach than
simply treating symptoms.

On the physical health side, we've learned that, and now you see plans that pay for things like gym memberships. The treatment of diabetes is much more sophisticated now, where you treat that condition as the condition that it is. It's a chronic condition, and there are things that you can do to prevent people from relapsing and paying higher cost services.

One of the things that we're excited about here in Philadelphia is that we are moving our system to that and MHA, who is one of the sponsors of this, and Elwyn, a leaders in that. But we know that things like peer services are very important, and it's hard for me to imagine private pairs paying for those services, but those are the kinds of things that we know make a difference long-term, and people being able to sustain their recovery, and again, reducing costs on the higher end.

Another issue that I -- that just highlights this issue, Secretary Richman was the leader of the Philadelphia system for many years, before I came to Philadelphia, and one of the things that she has done -- I think she's a genius, and I'm not saying that because she's here, but I really do,
because there are a couple of things that she has done
that, again, I think are important lessons for the
private sector.

The reality is that mental health and
substance abuse conditions affect, as I mentioned, all
parts of society, and integrated approaches to this
issue, I think, are enormously important. We spend --
I spend quite a bit of time, again, working with my
colleagues, but also, in working to integrate
behavioral health treatment in settings, non-
traditional settings, recreation centers, all kinds of
settings, so that people get early -- have early
identification, early access to care.

The last thing that I want to mention, and
I hope that this becomes much more visible nationally,
and that's the issue of health disparities. We have,
in this country -- people really understand the issue
of physical health disparities. People are not quite
sure what we mean by health disparities, when we talk
about behavioral health conditions, substance abuse
disorders and mental health.

In physical health, it is very easy to
identify health disparities. So, you know that people
of color have higher rates of cardiac disease. People
of color have higher rates of a whole host of issues.
Well, it turns out in mental health and substance abuse conditions, that the prevalence is about the same. The prevalence for schizophrenia is about the same, across populations, actually, across the world. The prevalence for bipolar disorder, for depression, all of those conditions, the prevalence is about the same. And if you're talking about substance use, the prevalence is actually lower for children of color, particularly African American children, than it is for their white counterparts.

But health disparities do appear, and the way that they appear is not in terms of the prevalence, but in terms of what happens to people when they have those conditions? So, you have people of color at a much higher rate, who access their care through hospital emergency departments, which is the worst place that you want to access care, or through the criminal justice system.

And so, I hope as you go forward with this issue of parity and making sure that people get the services that they need, that we as a country, are also looking at this issue of disparity and making sure that people get the kinds of services that they need, regardless of their racial ethnic background, regardless of their gender, regardless of anything.
other than the condition that they come to -- they seek treatment out of.

So, with that, I will end my comments, but I thank you very much for your interest in this topic. I hope my comments were helpful, and I hope that we are successful in making sure that everyone who has a mental health or substance abuse condition, gets the services that they need. Thank you.

MS. CORNELIUS: Good morning. My name is Sandy Cornelius. I am President of Elwyn. We're delighted to be the host, or hostesses, for the hearing today.

Elwyn applauds Congressman Kennedy, and Jim Ranstad in his absence, for their efforts to insure mental health and addictions equity, being proposed through the Paul Wellstone Mental Health and Addictions Equity Act.

For too long, mental health and addiction treatment have been given inadequate and inconsistent support and financial assistance.

Although I have a whole inch of paper here today, I think what I will elect to do is add to, rather than repeat, the comments that you've already heard. So, the one difference I have is that I am an employer, a large scale employer, and I will talk
about that.

Federal Legislation as the ability to create a national solution to inconsistent behavioral health care regulation. By imposing national requirements, the Bill could offer individuals who were in dire need of treatment, the opportunity to receive care early in their illness and throughout the length of their illness. Why would we want to limit treatment for disorders that we know now are controllable, if not yet curable?

The Paul Wellstone Mental Health and Addictions Equity Act would prohibit practices that have for too long, caused needless suffering, reduced productivity in the workplace and increased overall health care costs.

People are often forced to wait until the disease or symptoms become unmanageable, before seeking help. Knowing that only a limited number of visits are covered, or that the associated costs are prohibited, this forces patients to self-treat or minimize the treatment resources that they access. The impact of this is additive over a lifetime.

As an employer of over 2,700 employees, who work with individuals who have significant disabilities, I believe it is important to offer
support at many levels. This includes being able to offer mental health and addictions treatment at a comparable level to our physical health benefits, and to those being offered by Medicare and Medicaid. Our staff can only benefit from integrated health and behavioral health services.

While the cost to an employer and to their employees may initially increase, it is our belief that over time, the Paul Wellstone Mental Health and Addictions Equity Act will reduce the overall cost and overall stress to the 113,000,000 Americans enrolled in large health plans.

Elwyn thanks Congressman Sestak and his staff, for hosting this hearing and fully supports Congressman Kennedy and Ranstad for their efforts to insure mental health and addictions treatment equity.

Thank you.

(Applause)

CONGRESSMAN KENNEDY: If I could ask Estelle, could you elaborate a little bit more on your PH-95, in terms of how it would work with the S-CHIP program, because it sounds as if we're talking about, S-CHIP is coming up for re-authorization and what you have here in Pennsylvania, with respect to making kids eligible for Medicaid, regardless of parental income.
We're working on a Bill that would eliminate this family -- families having to give up custody of their children, in order for them to get state services. So, we're really interested in this notion. But could you elaborate on how S-CHIP re-authorization might factor into what you're doing here in Pennsylvania?

MS. RICHMAN: Let me first say that I think it's critically important for S-CHIP to be re-authorized, and I think that many of us have operated at a national level also, in advocacy groups, just consider that one of the most important pieces of re-authorization that needs to happen.

S-CHIP in Pennsylvania, as in many other states, is operated through a contract with the -- for Pennsylvania through the Department of Insurance to the Blue Cross system across the state. S-CHIP in Pennsylvania actually has a very limited behavioral component, and we, in deed, hope to see that change with the re-authorization.

CONGRESSMAN KENNEDY: We're going to plan to make S-CHIP with parity.

MS. RICHMAN: We absolutely need it with parity. In 1988 -- in fact, that was shortly after I came into the state, it was very clear that
Pennsylvania, like most other states, for families that had children with behavioral and health care problems, often had to give up custody to our Children and Youth System, to get the mental health treatment, which is another way of saying, paying for that mental health treatment, because of the prohibitive costs, particularly for residential programs.

MR. EVANS: How would they do that? Can you describe an anecdote, like how a family would do that?

MS. RICHMAN: They would -- they recognize their child has a problem. They would go to either the Children and Youth entity or to Court, and voluntarily give up custody. There was a category called "Voluntary Surrender of Custody", that they would do to be able to get this.

In return for that, the child would be placed more frequently in a residential treatment program, and families -- even when the treatment is completed, if everything went smoothly and that custody relationship could be terminated, which it always wasn't as easy for you to be given up, families were indignant that they had to give up custody to get a needed service for their children.

MR. EVANS: They had no way of kind of,
monitoring what the therapy was for their kids?

MS. RICHMAN: They had very little control once they gave that up. They basically gave up their parental rights, to be able to get that custody, and many states continue to that, even in Pennsylvania.

Although we've actually tried to pretty much control that, my guess is, there still is on occasion, in some our counties, some push towards that. But we've tried to eliminate it, and in Pennsylvania there's no need for it at this point.

In 1988, we really did go to what we call the loophole children, which just means the decision is made on the child's income. Child have no income.

Therefore, they were qualified, under our Medicaid statute, as being Medicaid eligible because they have no income.

Now, last year --

CONGRESSMAN KENNEDY: Can I interrupt again? Arthur, do families -- like, for example, in Philly, like -- could parents just call the police on their kids if they're -- it's a single mom and says, "I can't deal with my kid."

MR. EVANS: They do that.

CONGRESSMAN KENNEDY: I mean, we know there's a lot cases were kids are in juvenile homes --
waiting in the juvenile system, languishing, because there's no -- they don't have to wait. They can just languish in jail for a long time. There are not the same rights for kids as there are for adults. So, they're waiting for their -- can you tell us a little bit more about waiting for mental health treatment in the juvenile justice system and stuff like that?

MR. EVANS: Well, there are a number of parents who will give up their kids, simply because they can't manage them. The issue of children in the juvenile justice system, who need mental health services, as you would imagine, a fairly large proportion of those kids do need mental health services, and are able to access those services through our juvenile justice system, which is run by the child welfare system in Philadelphia.

MS. RICHMAN: We have several law suits here. One of them doesn't -- speak these kid's language very long.

CONGRESSMAN KENNEDY: Do you -- what's the time?

MS. RICHMAN: Usually, I can still tell you, it's longer for kids with behavioral problems than it is for kids otherwise, which usually can go through a system in probably less than 10 days. A
child with a mental health problem, probably takes about 40 or 45 days, because you're looking for some level of placement. That's actually down from the time I was in the system, where it used to run up to six months, to get the correct kind of placement. So, it is still a problem.

In deed, the majority of the children who fall under our loophole category are children from families who actually pay insurance, as you heard me say, but their insurance carrier will not, and employers frequently cannot, buy coverage. It's categorically eliminated, and the reason that we're addressing it -- we need to address it both at the State level, but having a -- having the Federal Government begin to set the standard, obviously makes it easier for those at State Government to be able to meet that standard and to implement.

CONGRESSMAN KENNEDY: Let me ask you -- Joe probably has questions too. In terms of the -- recouping any of those private dollars that you say that you end up having to provide services for, where insurance companies of people who do have the private insurance, but the insurance doesn't cover those kids, you end up covering.

Is there any way of recouping those
dollars or have you accounted for the kids that you are treating, that do have insurance?

MS. RICHMAN: As far as I know, we have not found a successful way to be reimbursed for those dollars. There is something called third party liability, or other party liability, where they will cover. We do require our agents, the managed care entities or any contractor, to go after third party liability. But some of these are categorical exclusions, or there are ceilings or there are such high co-pays.

What we're trying to say is that the -- a family should be able -- that pays a premium, if there is equality between their behavioral and physical health care, it never reaches the public dollar. We should not have to provide -- there should not be a way to cost-shift to the public system, because a ceiling is artificially low, or if something has been categorically eliminated from the policy.

CONGRESSMAN KENNEDY: On the whole idea, Arthur, of how the private system ought to look more like the public system, the public system does the case management, right?

MR. EVANS: That's true.

CONGRESSMAN KENNEDY: So, how do you get
the private sector to do that right, or any hope that you could ever get?

MR. EVANS: I think the costs are going to drive the private sector to do that. I think -- the public sector has had many years of managing the care for people who have chronic mental health and substance abuse conditions.

One of the reasons that case management was developed in the field was, recognition that without that, first of all, people aren't going to get the care that they need, and they certainly weren't going to be able to sustain their wellness, and I think that it will only be a matter of time before the private sector figures that out as well. Some more progressive, private insurers do have some case management. It's certainly not the level that you have in the public sector.

CONGRESSMAN KENNEDY: It's hard to understand why CMS is considering eliminating the re-hab option.

MR. EVANS: We think that that is full-hearted. It is -- it just -- again, I think that our field, again, if you look at the President New Freedom Commission Report and a number of other reports that have come out of SAMHSA, very clearly, the field is
moving to a recovery management, long-term sustain-
ability of people being in recovery. That takes a
different sets of tools then, frankly, our field is
equipped to.

We have a very acute care oriented system.
If you get sick, you can get hospitalization. What
we're not very good at and what we haven't built the
info-structure for, is to help support people in their
natural settings, in the community, so that the
probability of them relapsing is greatly diminished
and that they're not going to return to those higher
end services.

Again, I think this an area where the
private sector can learn from the public sector, and
we are radically, in Philadelphia, reconstructing our
system to do that and to have that kind of
orientation.

CONGRESSMAN KENNEDY: So many dollars, in
my emergency room in Providence, my ER doctor --
because we're a Trauma 1 center, so we get all the
trauma cases, so 80 percent of our cases are drug and
alcohol related. We get all the car accidents,
stabbings, knifings, gun shots and OD's, so it's all
drug and alcohol, he's says, so -- but there's no --
we stitch them up, but there's no -- it all gets -- it
doesn't get -- it's like the statistic here, for only accidents and homicides claim more young lives.

Well, accidents and homicides could be drugs and alcohol. But that's rated one. Suicide is the second leading cause of the death. Well, that could be mental health. So, is mental health -- mental health is the second and third and first, according to that.

And so, the point is, why can't see track -- and then I asked the President of -- the ER doctor, "Do you write them down on your discharge as drug and alcohol? What do you give them?" "Well, we're lucky if we give them a social worker, who gives them a pamphlet that says 'follow up', here's some drug and alcohol information."

In other words, the teachable moment is lost, because there's no requirement to write it up and code it. There's no coding that this is a drug event, this is an alcoholic induced event. No, this is an accident, this is a car accident, or no, this was an alcohol accident.

Why aren't we calculating those trauma dollars as alcohol events, and then aggregating those dollars, so that we could better proportion them? Because then those people, they tell me -- those
people are frequent flyers to the ER's. Can't we start looking at these budgets a little bit?

    MR. EVANS: Yes, there are a few things that are happening -- well, there's one thing nationally, and a couple of things locally in Philadelphia, that I think speak to the issue.

    I think you're absolutely right about the numbers of people who come into emergency departments, have a substance abuse condition that is related to why they're there. But because of how hospital emergency departments bill, that information isn't recorded. You record a primary diagnosis, admitting diagnosis, and often, the secondary diagnosis of substance abuse isn't captured.

    The Federal Government has issued an RFP several years ago, for screening and brief intervention. A lot of this work was done at the University of Connecticut and other places, Yale University, where people who are coming into emergency departments are screened for substance abuse and there is an intervention at that point, and what the studies -- early studies have shown, is that if you can screen and intervene early, that you actually reduce future admissions to the hospital. There are a lot of benefits for doing that.
We're also using that technique in our health clinics, a couple of our health clinics here, but that really goes to something that frankly, many emergency departments are resistant to and that is, dealing with the issue of substance abuse, and I say that because of my experience in New Haven, Connecticut, where I worked for several years with hospital emergency departments and screening people who have substance abuse conditions.

There is, to your point, tremendous stigma, and you will hear things, unfortunately, from health care workers like, "Those people are getting in the way of people who really need our help." That's not an uncommon thing to hear, in reference to someone who has a substance abuse condition, particularly, someone who is homeless or someone who doesn't have means. But you hear that quite often.

And so, there was a tremendous, I think, amount of resistance often, to dealing with this issue in hospital emergency departments. But to your point, I think that it is an area that is ripe with possibilities for intervening early in the lives of people and reducing the negative effects of substance abuse.

CONGRESSMAN KENNEDY: Well, what can we do?
At the local level, it seems to me, we need to do more.

MR. EVANS: Well, I think the screening and brief intervention strategy is a good one. It is documented as an effective strategy. It's something that the Federal Government has supported. I think it's an issue or resources to train and implement this in other settings around the country. But we have one model that we know works, and it really comes down to resources and will.

MS. RICHMAN: Just comment for a second, we have found -- we're implementing in Pennsylvania, a lot of pay-for-performance in our health care system, and we're finding that as we've done it, we're probably about in our third year on the fiscal health care side, we're getting the results. We do usually track something and then we apply a pay-for-performance criteria on it.

One of the places that we've seen significant change is the screening for adolescent health care. Under EPSDT, early periodic screening diagnosis and treatment, an adolescent should be screened for health care needs yearly.

In the beginning, our rates were probably down in the 30's, now they've listed up into the 60's,
on a pay-for-performance work hat.

You know, one of the things I would say that we need to do here in Pennsylvania, and it's well within my scope of authority to do, is that I need you to give me a secondary diagnosis when someone comes in for trauma in the fiscal health care, to be able to track it, to be able to set it into policy.

One of the things, unfortunately, we have found, unless you can get into some level of policy and some level of dictate, people often don't take notice. This year is also a year we're going to apply pay-for-performance and begin the process of pay-for-performance in behavioral health care.

I think the tax payers dollars, we no longer have the luxury of saying it doesn't matter, as long as you're doing good. It does matter. We have to justify the dollars. We have to be able to get our monies worth for tax payer's dollars, and therefore, we have to have outcomes that make sense.

I think the time has come. It's clearly -- taxpayers are holding us accountable for how we use public dollars, and we need to make sure we're making the integrative connections between our systems to get there. I think that as the forums continue and the debate continues, whether it's mental health and drug
and alcohol parity, or whether it's looking at how we use our dollars more effectively or how do we protect children or how do we get our school systems more effective, it all comes back to how do we see the entire person, how do we integrate our services and how do would hold ourselves accountable.

CONGRESSMAN KENNEDY: Well, if you could both give me your -- I mean, if there are problems with HIPA, as well, in terms of your ability to do this reporting, in terms of your discharge stuff, if you could give us your ideas, because we really need to get to the bottom of this. This is really driving costs through the roof, in terms of our health care costs, like you said. And Joe acknowledged, three times the cost for other -- all your other health needs, if you're going untreated in your mental health.

MS. CORNELIUS: For the hearing next year, I would ask you to remember that 113,000,000 Americans are covered by insurance -- by the health benefit coverage. But I, as an employer, have no ability to encourage my employees that I give pay checks to regularly, to practice wellness, including treatment for addictions or physical health conditions.

We have a wonderful carrot and stick
opportunity to change the behavior of many, many people, and also improve it. So, when we see you next year, we'll talk more about that.

CONGRESSMAN KENNEDY: Next panel, please.

Thank you, guys.

(Applause)

CONGRESSMAN KENNEDY: Joseph Rogers, Debbie Plotnick, Ivy Silver and Theresa Landis. Joseph, thank you very much for your work on mental health association. Mental Health American Now, thank you for their good work.

MR. ROGERS: Yes, I'm on their National Board and actually was the one that proposed the title change, though we have not changed our local association. We're working on it.

Thank you very much, Congresspersons, for having us here. My name is Joseph Rogers and I'm President of the Mental Health Association of Southeastern Pennsylvania, part of Mental Health America, and we're one of the sponsors at this hearing.

I'm very concerned about being able to obtain full health coverage and not being discriminated against, because of my diagnosis of serious and persistent mental illness, bipolar
disorder.

At the Mental Health Association we are very concerned about this issue, in part, because the majority of our staff have mental illness. There has been many times that my life was at risk because of insurance company discrimination against people with mental illness, and I share this experience with tens of thousands of Americans.

Since 1980, I've been employed in positions that have provided some of the best private insurance coverage available, but in every single instance, there's always been serious discrimination involving my mental health needs. The biggest problem is the arbitrary limits of coverage.

Mental illness is often episodic. As true with many people who have mental illness, there are times when I'm doing very well, but there are also times when I badly need help, often because I become suicidal. But when I seek help, the help I get is determined by the limits on coverage that exist in every plan I've ever had.

Unlike my physical health care, if I need psychiatric hospitalization, that hospitalization has an artificial cap on it. From most of my working life, under private insurance, that cap has usually
been 30 days.

Now, with managed care, that cap seems to be more like three to five days, even though the plan might say 30 days. But when I have been acutely mentally ill, even 30 days has just not been enough. It may become -- it may sometime to become stable -- it may be some time to become stabilized on new medications, because one of the reasons I get sick is that medications I am on have stopped being effective. This is kind of a common situation for a lot of people with bipolar disorders, where you're on medication, it works, then for reasons we don't quite know scientifically, it stops working. Unlike many medications for physical illness, such as penicillin, psychiatric medications are not one size fits all. Finding the right medication and the right dosage may require some experimenting.

In other words, just getting stabilized on an effective medication can take more than the 30 days allotted and a lot of times, you have to do that in in-patients with bipolar disorder. You're usually - when you're seeking help like this, you're usually in a so-called manic state, and quite honestly, being out in the community is not good for my health, and things like driving and other things, are not good for other
people. Heaven for bid it takes one day more. I will find myself on the street, having to deal with this problem on my own.

Compare this to treatment for my diabetes, a condition for which I can get help, as long as the doctors believe I need it. This is not just a luxury or a matter of convenience, but a life threatening issue.

For example, one time when I was hospitalized, the doctors felt it was important that I stay, but the insurance company, against medical advice, decided it was time for me to go. This left the doctors with the dilemma of whether or not to take the risk of keeping me and never getting paid, or putting me on the streets when I was actively suicidal.

Luckily, because I'm an advocate and I have lots of friends, including Estelle Richman, who were advocates, we were able to get the State to step in and say that they would cover the hospital care of me, past the insurance companies coverage. So, that dumping people onto public role. But I know that most people in my position would not have been so fortunate. Many of us would end in prison. We would end up being kicked out and possibly, in prison, more
dumping on the public system.

    Like many individuals who have mental illness, I face these kinds of dilemmas every time I have a crisis. Will there be coverage or not? Well, have I used up my limits or not? Will the insurance side that I don't meet hidden and undiscoverable criteria for treatment, which they won't tell you. You go and say, "I need treatment." The insurance companies say, "You're not qualified for treatment." You say, "Well, what are the qualifications for treatment?" They say, "Well, that's proprietary. We don't tell you that information." When I say hidden, I mean, when you ask the insurance company for the criteria, they say that is proprietary.

    The cost of the individuals into society is enormous, when folks like me fall through the cracks. If you don't simply self-destruct, our behavior may become a problem to the community. So, I might go to jail or a homeless shelter, both of which would cost society a lot more money.

    I hope that no one in this room believes that such cost shifting is a good thing, and again, I applaud the Congresspersons for addressing this important civil rights issue.

    (Applause)
CONGRESSMAN KENNEDY: If I could just interrupt for a second, because I imagine this is going to be a recurring theme. We're going to be introducing a companion build-a-deal with medical necessity issues, basically, the patients Bill of Rights issue. This Bill doesn't address that. It is simply a parity Bill.

But clearly, the real rub in all of this, for many people, is the denial of care, the denial of benefits, the managing of benefits, the whole HMO issue. That affects every health care part of our health care system, and we need to address that. That's where all the money is, basically.

But frankly, the insurance companies are so greedy, that we can't even get them to agree to first, agree to cover all medically diagnosed mental illnesses in the DSM IV, forget them managing the benefits under those illnesses.

They want to define what constitutes a mental illness, not let doctors and clinicians define it under DSM IV. Insurance wants to define them. So, they want to define out eating disorders, as not constituting mental illness. They want to define out, possibly, drug and alcoholism is not part of a mental health package, or whatever, and that's what we're up
against.

We have to win the first battle, which is, we've got to cover all mental illnesses. That's what this Bill is about. The next battle is then, once we've got them covered, then we have to go at them, in terms of making sure that -- then they provide the benefits that they've covered. So, that's the battle of making sure that they're accountable.

So, that's the second Bill, and that's a companion Bill that Joe and I will be fighting for as well, and I might add, in terms of your point, that there isn't transparency, the one thing that we will have in this Bill is transparency, which says that we will have in this Bill that their policies and criteria for their policies, have to be absolutely transparent, meaning, you can to go and get their policies and know it all there. They cannot deny you.

You have to be able to see their whole list of criteria. That's absolutely guaranteed under our ERISA already. But they play that game of --

MR. ROGERS: I just want to totally agree with you. I think our first battle is get them to even sort of say that we have some sort of level playing ground. But I agree with you 100 percent, and that's why this Bill is so important, and thank you
for championing it.

CONGRESSMAN KENNEDY: Debra?

MS. PLOTNICK: Good morning, Congressman Sestak, Congressman Kennedy, ladies and gentlemen. My name is Debbie Plotnick and I've come before you this morning to talk about two subjects that are painful and difficult to speak about publically, my daughter's life threatening illness and my families finances. Unfortunately, because of the issue before us today, they are inextricably tied together.

My husband Michael and I are representative of many of your more fortunate constituents. We are well educated. We live in a lovely home in a nice suburban township, and we are the parents of three wonderful children, two sons and a daughter.

Today, all of our children are doing well. Our elder son, Alex, is in graduate school and our younger son, Max, is a college sophomore, and Ashley, our middle child, who just had her 25th birthday on Sunday, has a college degree. She graduates in May from nursing school and she was married last June.

But just over 10 years ago, my husband and I endured a terrifying four year period, where we had every reason to fear that our beautiful and talented
daughter wouldn't live to see her 18th, let alone her 25th birthday.

Ashley has an illness that affected my father and a number of others in my family. It is an illness with a high mortality rate, but is also one that with treatment, can be successfully managed. But because the illness that runs in my family, bipolar disorder, has been deemed different from other afflictions that have a genetic basis, such as diabetes and sickle-cell anemia and cystic fibrosis, my family was doubly affected.

Getting Ashley the life saving treatment she needed brought my family to the verge of bankruptcy. This happened in spite of the fact that we had one of the best health insurance plans available. My husband had a healthy income and we had some assets, money saved for the kid's college educations.

Our so-called excellent health insurance fully covered the costs of too many emergency room visits to sew up Ashley's split wrists and to pump her stomach. It even covered all but a small deductible for ambulance rides and intensive care units, for the times we weren't sure she'd make it.

But when it came to paying for services of
the doctors specially trained to treat our daughter's mental illness, we were shocked to learn that our insurance only covered half of the fees charged by those specialists, and no matter how sick Ashley was, the insurance only permitted her 30 visits per year to those specialists. And when Ashley required specialized hospitalization, although our insurance did cover the full cost for 30 days, that meant 30 days over the course of her entire life, up to the maximum life time amount for all psychiatric services, which at the time was $10,000.

My husband and I knew that if we could keep our daughter alive long enough to gain the maturity to manage her illness, she stood an excellent chance of having the successful life she has today, and we were determined to give her that chance.

It didn't take long to use up all the benefits and to go through our savings. There were many weeks that I stood at the supermarket check-out and cried because I had to charge the groceries to my Visa, because it was the only way to feed my kids.

The hospitals also took credit cards, but the doctors usually did not. Our cash went to pay them and credit covered the rest.

It's been over 10 years since we incurred
tens of thousands of dollars of debt to save our
daughter. My husband and I keep our old cars limping
along. We haven't been able to pay off as much as our
debt as we'd hoped, because the college financial
aides offices don't care if you have a jewelry habit,
a gambling addiction, or if you've used all of your
savings and then quite a bit more, to save your kid.

They don't ask about debt, let along why
you've incurred it, but we promised our kids their
educations and we've kept that promise. So, we're
okay with the fact that it will probably take another
decade to pay off Ashley's medical expenses.

I didn't come here to ask you to feel
sorry for privilege upper-middle class families like
mine, that can't afford a vacation and have to fix the
roof on their house themselves and drive old clunkers.

I came here to illustrate that even with considerable
assets and even when financial ruin has been avoided
and going into the public system has also been
avoided, the grave problems caused by the inequities
in our insurance coverage will afflict many families
for decades to come.

Please, let's stop doubly afflicting
families who have the misfortune to have the wrong
type of illness. Thank you.
MS. SILVER: Good morning. My name is Ivy Silver and appreciate the opportunity to speak with you today. Mothers believe that we have the intuition to know when our children are ill and in distress. I thought I would know the signs, since I had been bulimic as a young adult, and I believed that if I promoted a love of food and cooking, if I avoided criticizing my children's appearance, and promoted a healthy appreciation for one's body, I could prevent a repeat of history.

We weren't told that our daughter's early childhood experience with depression and anxiety increased her chances of developing an eating disorder.

Our family never saw Rachel's hunger or her pain. But her teenage friends did. Thankfully, they came forward after only a few months of extreme eating behaviors. But by then, her hair was already falling out. She was suffering from severe chest pains, that the family practitioner called growing pains, and she had collapsed in after school sports from dehydration and electrolyte imbalance. Her coach never called us.

We learned of her disorder early enough,
so that Rachel received care after the onset of symptoms, making her recovery that much easier, before she became infertile, developed osteoporosis, damaged her heart for life, or even died.

Eating disorders, which include anorexia, bulimia and binge eating, happen because of a variety of factors, due to genetic pre-disposition, societal influences on diet and image, the result of emotion pain or trauma. They are not just diseases of the rich and middle class. They affect not just girls and women, but boys and men as well, and are prevalent across all races.

A significant part of our story was learning about the insurance limits when it came to mental health care. The irony of this is, I own an employee benefits consulting practice. This was suppose to be my area of expertise. We had to learn the dire realities of limits on health care coverage. We had to learn the agony, the terror and the long-term financial implications that those limits created.

Recovery takes place over weeks and months and years of continuous care, and its duration is a function of a variety of different variables. Thirty-five thousand dollars a month for in-patient care. Thousands of dollars a week for intensive day
treatment, and if you're in out-patient care, a
typical week includes bi-weekly visits to a therapist,
a psychiatrist for medication checks, a nutritionist
for weigh-in and food support, weekly family therapy
visits and maybe even primary care physician
appointments, for the complications that so frequently
come with eating disorders. Hundreds and hundreds of
dollars, week after week, month after month.

For our family, the two years of treatment
cost more than $27,000 in out of pocket expenses, and
yet we had a high caliber national carrier plan. Our
mental health limits were considered standard and
you've heard them all here earlier today.

For many families, second mortgages are
taken out, savings are drained, siblings are told that
they can't afford colleges and vacations are
cancelled. Bankruptcy is a reality, or proper care is
not provided, because there's nothing left to
mortgage.

The stress for paying for care makes an
already painful experience even more anguishing,
anguishing for the family, but excruciating for the
patient. Heart attack victims who have insurance
don't go bankrupt to save their lives. No one should
have to mortgage their future to save a life.
Our of her discriminatory and humiliating experience of knowing that we were having to draw deeply into our personal financial resources for care, our daughter founded A Chance to Heal Foundation. Rachel was appalled that girls and boys were sent home from hospitals after just one or two days of treatment, because insurance companies dis-allowed anything more.

She was even more disheartened to know that most people with bulimia can't even get in-patient care because the protocols of care are weight based, not behavior based.

Rachel survived and went on to create A Chance to Heal Foundation, to educate people and prevent eating disorders, to advocate on behalf of those with eating disorders and to change the way in which our country provides care for mental illness.

Our State Insurance Commissioners don't question the assumptions of unequal care. As a benefit consultant, I know that untreated depression increases the cost of medical care by more than 30 percent. Disease management programs that actively address mental health help reduce the cost of care.

A Chance to Heal is working to change the culture that exists today. We fully support the Paul
Wellstone Mental Health and Addiction Equity Act. We all need to say what Rachel said, "This has to change." We need to do what her friends did, when they stepped forward and said, "You have to do something." Thank you.

(Applause)

MS. LANDIS: Good morning. Thank you for the opportunity to talk about the need for insurance parity. I want to give you some history of my experience with private insurance and how it failed my son and I.

I am a single mother of two boys and a girl. My younger son, who is now 15 years old and is diagnosed with bipolar disorder, has had behavioral difficulties for several years.

When he was 10 years old, his behaviors were becoming more and more erratic, and I was attempting to get mental health services for him. I had private insurance through my employer. I called my insurance company and they gave me a list of therapists. Although my medical appointments and my children's visits to their pediatrician did not have a co-pay, I was told our mental health treatments did. This was a concern, since I was supporting my family with a limited income.
When I went to my son's therapy appointment, I asked about these co-pays and whether there was a sliding scale. The therapist suggested that I try to get my son on to CHIP, which is Pennsylvania's Children's Health Insurance Program, because that program would pay for everything.

I also discovered that my private insurance would only cover a total of 30 mental health visits a year for myself and my three children.

The therapist also thought that my son might need medication and I didn't have a prescription coverage with my private health insurance plan. That was another reason the therapist thought I should get my son on to CHIP.

At the time, my life and my children's lives were in shambles, because of child abuse by my husband, for which he subsequently served jail time. I was also working two jobs then, and all three of my children needed therapy. Complicated insurance problems were not something I needed on top of all of that.

Following the therapist's advice, I dropped my children from my private insurance and signed up for CHIP. Once my son was enrolled in CHIP, he had to get another psychiatric evaluation, which
CHIP paid for 100 percent. My son was diagnosed with childhood depression, oppositional defiant disorder and intermittent explosive disorder.

The psychiatrist recommended wrap-around services. That's services provided by a team of people, including a behavioral health specialist, a mobile therapist and therapeutic staff support, and it was the psychiatrist who suggested that I enroll him in medical assistance, since CHIP doesn't pay for that kind of thing.

Treatment couldn't begin until he started medical assistance, which took about four weeks. During that time, he had an incident at school. He was being bullied on the playground and turned around and said, "If you don't leave me alone, I'm going to kill you." As a result, he was arrested a jailed. He was 10 years old at the time.

Sometime earlier, the school had assigned an aide to him, but the aide did not have mental health training, and therefore, was of no help to my son. If my insurance had covered wrap-around services, there would have already been a therapeutic support staff in place for him, rather than an untrained aide, provided by the school district. This incident might have been prevented.
Also during that four week period, that we spent waiting for medical assistance, my son became suicidal. I took him to crisis services twice. When he finally qualified for medical assistance, he eventually received in-patient treatment, which he desperately needed.

It was not easy to navigate through the various systems. Also, for close to a year thereafter, medical assistance kept inserting a code indicating I had alternate insurance. What this meant was, any time my son received services, medical assistance kicked it back to me to be submitted to the primary insurance, which I didn't have anymore.

I compare all this with the fact that if my son had been diagnosed with cancer, although it would have caused enormous emotional anguish, I would have not had to go through all the trauma of figuring out how to pay for his services. In other words, both diagnoses could cause anguish, but the mental health diagnosis, the anguish is doubled.

My son does not have cancer, but he did have repeated ear infections and had to have tubes inserted in his ears. That was fully covered by my private insurance and is as simple as two doctor visits.
I would like to mention, that it has always been my goal to support my family without needing help from the State. I graduated from college with honors in 1998. While I was a student, we were on medical assistance. But as soon as I graduated, I got a job and had private insurance, so I would no longer need help from the State. Little did I know that not too long afterwards, I would have to re-apply for State benefits.

I am hopeful that the passage of the Paul Wellstone Mental Health and Addiction Equity Act will mean my son will be covered by my private insurance, saving tax payers money and myself esteem. Thank you, again, for your time and attention.

(Applause)

CONGRESSMAN KENNEDY: Well, thank you, all, for your very powerful testimony. It's so indicative of why we need to pass this Bill. It will be very useful to us, in our efforts to bring this to light, because we'll be bringing this through personal testimony. There's nothing more powerful. You can read all the statistics in the world, but giving your testimony and -- Joe and I will be -- we're going to be doing special orders, after we do these series of hearings across the country, and Joe will be reading
testimony from you all, from his district, during these special orders and that's -- there's nothing like telling these personal stories, that's going to make the difference, because that's what's going to move people.

So, thank you so much for sharing, and I know it's painful, but it's so much a part of the effort to make these changes possible. Thank you.

CONGRESSMAN SESTAK: May I ask one question. As a representative here, what is it, as we go down the road here, that will take until we get this passed and then beyond that? What would you say I could do better to help?

MR. ROGER: Well, I think -- my thinking, we were looking at the budget right now. Obviously, the existing Federal budget, which I know that you're paying close attention to, and I think it's -- as we look at the Federal budget, there's a lot of money that's being cut from the Federal budget, to specifically address the needs of people's illness and substance abuse.

So, obviously, one of the things our plea to Congress and the Senate is, is to -- for those cuts in the President's budget, because not one dime can be spared. One of the things I'm concerned about, and
obviously, you're all concerned about, is our Veterans.

Veteran benefits cover to a certain degree. But a lot of our Veterans need to -- go public, or are in private systems. My brother is an example. His situation is, he was dropped by the Veteran's system and he's now basically in private care, and he's having to pay his own. Because he's covered by the Veteran people, he can't get Medicaid and stuff.

Veteran's Administration has decided, for various reasons, that he is no longer eligible, and he is now having to do all of this on his own, and he doesn't have the money to do it, and I'm having to help him.

So, for Veterans, many of the Veterans face these same problems, when the come into the community. Many of our National Guard people don't get the same kind of Veteran benefits, and as based -- go back to work and are looking at private insurance to cover them. Even if you're talking about minor situations of adjustment, not post-traumatic stress syndrome or any of the major issues, the care that they need sometimes cost so much, that it just sort of breaks the bank. So, anything you can do in that area
would be great.

MS. SILVER: A Chance to Heal Foundation, one of the things that we have done, is we have tried to figure out what is the best way to provide information and education, and what we have come to find is that the medical community itself is uneducated regarding mental health, that there is not enough training within the medical schools and within continuing education for practitioners themselves.

I think every one of us in this room, who has had to deal with mental health, has suffered through the process of trying to find providers that actually know what they're talking about and know how to actually treat the specifics of the conditions that our loved ones are needing care for. So, there is very little training in medical schools.

In addition to that, what you're finding is that because facilities are not receiving reimbursement in the levels that they need it, there are fewer and fewer facilities that actually have -- we have access to, that we have to travel such distances in order to receive the care, that it actually pulls apart the families, just trying to get access to these providers and facilities.

CONGRESSMAN SESTAK: That's the example of
the doctor saying growing pains for your daughter.

    MS. SILVER: Yes.

CONGRESSMAN SESTAK: Rather than --

    MS. SILVER: Absolutely, among other things, correct.

CONGRESSMAN SESTAK: Thank you very much.

CONGRESSMAN KENNEDY: By the way, we've got legislation in -- on eating disorders, to -- and on mental health, both with respect to requiring through the general -- graduate medical education. We're going to be passing reform legislation on the Medicare Part D. You know, Congress funds graduate medical education through Medicare, and we can impose questions on the GME through the Boards, through the Education Boards, that students take for their medical boards.

So, if you put questions on there on mental health, then the docs then have to say, "Well, if I'm going to take these questions, then I need the curricula to take them," which means, that it forces them the medical schools to teach more in that area. But if we put more questions on the Medical Boards, then they have to teach more.

In addition to that, we're finding ways to require more, in the way of credits, in terms of
continuing education, all of the certificates for medical education. Continuing ed, all docs and medical professionals are required to take continuing ed credits every year.

We're going to have, as a requirement, those credits include credits in mental health, and that includes for everybody, pediatricians, geriatricians, obstetricians, everybody, because every physician needs to be on top of mental health, and we've got a specific Bill on eating disorders, to get more awareness out there on that.

On the parity, the big problem here is, the parity of benefits doesn't mean parity of pay. The big problem is, you can have the benefits, but if the providers aren't being paid the same as other providers, then there aren't going to be as many providers. So, we've gone to work on that, and we've got to work on getting more providers in the field, which means we've got to get loan forgiveness, because no one is going to be out there in the field.

So, we've got, in the higher ed Bill, we're going to be working on legislation to have -- designate in the high need category, child and adolescent mental health providers -- professionals, as those in the high need category, which will qualify
them for loan forgiveness under the Higher Ed Act.

   So, like I said, there are numerous different Bills that we're going to be following up on, just so you know.

   (Applause)

   The next panel, Allen and Carol, from PRO-ACT and NAMI.

   MR. MCQUARRIE: First of all, I'd like to thank Congressman Sestak for giving us time in your office on a Saturday, when we competed with a family day. I appreciate your time and I also appreciate your time, Congressman Kennedy.

   My name is Allen McQuarrie. I represent PRO-ACT, which is a Pennsylvania Recovery Organization, attempting to achieve a community together, made up of people in recovery, their family members and others who have suffered from addiction to alcohol and other drugs, as well as co-occurring illnesses.

   We're grateful to Congress for its effort to establish insurance parity for mental illness and addiction treatment, because without parity, many who desperately need treatment will not receive it, and this could and would jeopardize their ability to achieve recovery and live productive lives in a
I have been recovering from alcohol addiction for 23 years. I have a son who is in addiction recovery for seven years, and a brother with a similar history, for five years.

Congressman Sestak, my son spent 21 years in the Navy Seals, just retired. My brother was also a Navy weather man.

We're among the lucky ones whose insurance policies and practices paid for the care we needed. You heard about the care that wasn't provide. I'd like to speak to the care that was.

I got detoxification, 30 days of in-patient, 24 weekly after-care sessions and my family received family therapy, which is unheard of today. I also have a year of counseling for co-occurring illnesses. I am fortunate because my insurance policy, paid for by my employer, negotiated by my union, made it possible for me to get the kind of treatment that people are attempting to get in the State of Pennsylvania under ACT 106, which provides minimum mandated treatment requirements, similar to those which I just described.

One reason I testified today is to make sure that the Paul Wellstone Mental Health and
Addiction Equity Act includes strong enough language that it would not supercede the hard won statutes that are included in the mandates contained within the laws, such as ACT 106, and laws that may exist in 43 other states who have put similar legislation in place.

I'm also here to testify on behalf of half of the insured Pennsylvanians who are not covered by ACT 106 because they fall under ERISA. The Federal Government regulates approximately half the insurance policies written in Pennsylvania. They do not get the same kind of benefits that are minimally mandated in ACT 106.

I urge the passage of this Act on behalf of my brothers and sisters who desperately need that recovery, whose treatment protections are not covered by our progressive statutes, that could be a standard for Congress to heed.

For more than two decades, we have tried in Pennsylvania to remove barriers to treatment for addiction and co-occurring illnesses. We urge Congress to protect those legal requirements for a continuum of care for those who we represent in Pennsylvania.

Two most important things I find -- I
don't want to repeat what others have said, is that we need to preserve whatever we can to get access to care. We need to protect the doctor's ability to authorize and designate the care we receive.

(Applause)

Had it not been for the treatment that I and my brothers received, I wouldn't be here to testify today.

(Applause)

MS. CARUSO: Good morning. If I can just preface my remarks with a little bit. The previous panel kind of stimulated some thoughts for me, and some concerns that are very near and dear to my heart, so far as children and adolescents and the lack of child psychiatrists in either the public or the private sector, is just for the very reason you had mentioned -- just the lack of sufficient reimbursement rates for this, and also with adults.

But I think for kids, what we see is a lot of kids that are over-medicated or not medicated at all, because due to stigma, families tend to go to their family doctors who are not educated in mental health treatment, are not educated in the medications that are available for kids, and tend to over-medicate, and I think this is one of the big issues
that gives psychiatry and behavioral health a very bad name, and something we really need to do something about. So, I really appreciate what Representative Kennedy said about educating, continuing ed credits, across the board in medical practice for mental health. I really appreciate at.

As far as the Veterans, I can't say enough about what we need to do for all the time in NAMI, just the lack of -- (microphone breaks up)

So, there's just not enough that we can do. So, I really appreciate your participation in this, Representative Sestak.

CONGRESSMAN KENNEDY: And I just would say, I am -- we're pushing for -- one of my visions is for us to push for much more behavioral research at -- in IMH, because I am -- really, there's too much, in terms of the biologicals and finding the magical pill to solve everything, when we know that behavioral interventions have enormous affect, in terms of changing the brain chemistry and behavioral interventions, in terms of mitigating disability and so forth.

As a recovery addict and alcoholic myself, with a co-occurring disorder of bipolar, I mean, I've seen how -- what an important part cognitive
behavioral therapy has played in my own recovery, along with medications. But it's certainly a big part of recovery, and I just find that we, in our culture, just so want the pill and we want to go right for the biologics.

And so, I certainly am for us investing more and want to find a way to get an FDA equivalent of behavioral therapy, so we can start validating evidence based interventions, in terms of behavioral approaches.

(Applause)

MS. CARUSO: Thank you. In my testimony, I mention mental illness, with the understanding that the vast majority of persons with mental illness also have a co-occurring substance abuse disorder. And also, I just wanted to thank you -- I want to do this before I say thank you at the end, but thank Representative Kennedy and Ranstad, for continuing the vision of Paul Wellstone, who was building an active advocate in this area, due to his -- he had a brother with schizophrenia, and of course, it's the lived experience, as you said before, that usually moves systems and of course, this is a great example of that. So, I really appreciate that.

Good morning. I am Carol Caruso,
Executive Director of NAMI Pennsylvania, Montgomery County. NAMI is the National Alliance on Mental Illness, a grassroots advocacy organization, composed of persons who live with mental illness and their families.

There are 60 NAMI affiliates across the Commonwealth and 1,100 nationally. I am also a former President of NAMI Pennsylvania and currently serve on the NAMI Board of Directors. I appreciate this opportunity to speak today on this extremely important issue.

Research proves that effective treatment can support the recovery of a person with mental illness and help them continue with or return to a full and productive life. However, recovery is not possible when limits to treatment are imposed. In addition to delaying recovery, such limits also promote stigma that discourages those in need from pursuing necessary care.

Insurance limits on mental health care are discriminatory. Mental illnesses prove to be just as real an illness as diabetes or heart disease. Limits on treatment of those diseases, such as the limits imposed on mental illness, are unheard of and would not be tolerated. Yet thousands of individuals and
families spend their life savings, run up credit cards
and plead with providers to wait patiently for payment
due to this reality. Children fail in school and in
relationships. Adults lose employment and often
deplete their own or their family's resources in many
instances requiring them to go on the welfare roles.
It is time to end this practice of the two-tiered
system that is currently in place.

With nearly one in four Americans over the
age of 17 suffering for a diagnosable mental illness
in a given year, mental illness in some way touches
every American family. We can no longer afford to
have people feel ashamed or guilty because of these
conditions. We must act now to see that they receive
the help that they need, when they need it and for as
long as they need it.

Time is now for America to wake up to the
fact that mental illnesses are medical in nature and
deserve to be treated as such. We will no longer
tolerate ourselves and our loved ones who live with
mental illness being treated as second class citizens,
due to discriminatory practices, such as we experience
with our health care system.

We will no longer tolerate instances, such
as refused payment to an ambulance company for
transporting an adolescent who has taken an overdose. We will no longer tolerate limited numbers of out-patient visits when psycho-tropic medications, when they are first prescribed or during times of increased stress, require closer monitoring than once every six weeks.

The time to end these injustices is now. The time for parity is now. On behalf of our thousands of NAMI members and the hundreds of thousands of children and adults who live with mental illness and their families, I urge you to take this message back to Congress that we will wait no more. Thank you.

(Applause)

CONGRESSMAN KENNEDY: Thank you. All I would close with is, Allen, particularly, within the recovery community, we've got to get away from those who belong to 12 step programs thinking they all have to be anonymous. They can be part of a 12 step recovery program and still be citizens of this country, okay, and they've got to be reminded that "Dr. Bob" testified before Congress.

That's part of -- that's a fact. So, we --- they only way -- we're our own worst enemies in this, you know. As, we're the biggest disability
group out there and we're going to get rolled politically, unless we stand up for ourselves. And if all they know about alcoholics is when we're drunk, then that's all they're going to know about us. But if they know about us when we're sober, then we put a much better face on it, and that doesn't mean we have to say -- we have to talk about what program we're part of, but we do have to tell our story as sober alcoholics, because we have to give a picture.

But I get more mail from folks, and it's not out of attribution to me and what recovery program I'm in, but of course, the press always says that I'm part of a well known 12 step program, not of any mention on my part, and I get more mail and people from the program saying I'm violating the 11th tradition and it's just -- it's just so -- people are so obsessed with it, and I just wish that people could be more concerned with the fact that they're getting discriminated against and they ought to be more wild and worked up about the fact that insurance companies are treating them like they are, and more -- and 175,000 of their fellow alcoholics are dying every year because 300,000 of them are being denied treatment, than whether I'm getting outed, because I happen to be a public figure and the media is so un-
savvy about -- which they should know better, because of the tenants of the programs, to know better than to write down what my 12 step program is -- but they are -- they don't know the traditions and they don't know the 11th tradition. So, how can you blame them?

But that -- take that aside, forget about it. We've got to get out there. This notion that we're standing anonymous is just killing us. It's killing us.

MR. MCQUARRIE: Actually, you are referring more on the tradition of Marty Mann, a woman who was active when the 12 step program came into existence and did a lot of testimony, and she ran into many of the same kinds of problems you are, putting a face and a voice on recovery.

You have no idea how heart warming it was to see you and Jim Ranstad on the front page of the New York Times, and I appreciate all that you do for the recovering community. I'd like to thank you publically.

(Applause)

CONGRESSMAN SESTAK: Can I ask you a question? As I'm passing through a crowd in the last few days, I've been kind of -- someone says, "I need to come and talk to you," so that inadvertently, the
Bill here doesn't somehow do damage to 106. Do you know what they're talking about?

CONGRESSMAN KENNEDY: The Senate Bill preempts State law.

MR. MCQUARRIE: Yes.

CONGRESSMAN SESTAK: Okay.

CONGRESSMAN KENNEDY: What we have to be very careful of -- our Bill does not. That's why --

CONGRESSMAN SESTAK: Okay. So, it's the same?

CONGRESSMAN KENNEDY: -- you have to be very careful. Our Bill -- we're going to unveil our Bill probably next week, and that -- we make it very clear that our Bill is the floor, and not the ceiling, meaning, if the states want to go further, states can go further. But we're on a real battle.

The insurance companies have come to the table because they want universality in mental health, because they only want to write one policy nationwide.

MR. MCQUARRIE: Right.

CONGRESSMAN KENNEDY: The problem with the Senate Bill, as currently written, is it will preempt all state laws, and it will be the ceiling, meaning, a Federal Judge -- if you've got a more generous law here in Pennsylvania, will say Federal law applies and
forget state law. Throw it out the window.

MR. MCQUARRIE: Yes.

CONGRESSMAN KENNEDY: All your hard work, getting more generous benefits for drug and alcohol coverage is out the window.

MR. MCQUARRIE: Well, not only that, but getting access to those benefits. We've had a struggle, even with our law, getting the insurance company to obey the statute.

Pete Longback, who is one of the co-authors of the Bill --

CONGRESSMAN SESTAK: Yes, that's what I've heard.

MR. MCQUARRIE: -- testified at one point that the insurance companies break the law in the State of Pennsylvania every single day. So, that's what we're concerned about.

CONGRESSMAN SESTAK: I haven't had time, and I apologize, to sit down and go through --

MR. MCQUARRIE: That's okay. You're coming along fine.

CONGRESSMAN SESTAK: I was going through --

CONGRESSMAN KENNEDY: That's the right question to ask. You know what? That's the question we want more members of Congress to ask, before this
whole process is over. That's the kind of question. If we get more members of Congress to ask those kinds of questions, we'll get the better Bill of -- both, out of the Congress.

(Applause)

CONGRESSMAN KENNEDY: The fourth panel is Allen Hartl and Kimberly Best.

MR. HARTL: Good morning. My name is Allen Hartl. I am the Executive Director of Lenape Valley Foundation, which is located in Doylestown, Pennsylvania. Lenape provides mental health, mental retardation and early intervention services to children and adults.

I am going to limit my remarks to only some of what's written because of the time this morning, but you do have my written remarks.

First, I would like to thank Congressman Kennedy and Ranstad for their leadership and courage and promoting parity to legislation, for hosting these nationwide forums and I'd like to thank Congressman Sestak for making sure it came to Pennsylvania.

Today, besides Lenape Valley Foundation, I also represent the Pennsylvania Community Providers Association, commonly known as PCPA. PCPA represents over 200 community base providers of mental health,
mental retardation, substance abuse and other human services.

Our host today, Elwyn, I'm proud to say, is one of our PCPA members. These members provide services in over 1,100 locations in all 67 counties of Pennsylvania and as the premier Pennsylvania Association, with members providing both mental health and substance abuse services, PCPA is in a unique position to comment on this legislation.

The legislation is important because treatment for mental health and substance abuse issues works. One need only speak to some of the very people who are here today, the consumers and family members, to confirm this. All Americans must be afforded the opportunity to seek such treatment when the need arises. The 1999 Surgeon General's report on mental health and the 2003 President's New Freedom Commission on mental health both make this point, stating that such conditions must be treated with the same urgency and status and physical health problems.

Assuring that health insurance plans recognize this and provide coverage in a manner equitable to other health conditions is a significant step forward in improving the overall health of our citizens.
In my prepared remarks, I talk about various statistics at this point. I'm going to skip over those, because you've had lots of statistics this morning. But there is overwhelming evidence of the cost and profound deleterious impact of not treating behavioral health disorders. The very mean for this legislation points to the history of health care plans not including equitable coverage to their subscribers.

Federal legislation is needed if this is to be reversed. If protections are imposed to insure behavioral health treatment, great things can be accomplished, as evidenced by the unparalleled success of Pennsylvania's car load of Medicaid behavioral health services and its health choices program.

These protections should not be limited to certain diagnoses, but rather, should encompass all behavioral health diagnoses contained within the existing Diagnostic and Statistical Manual.

The brain/body connection is well established and an array of effective treatments is available. Anyone who can benefit from treatment should not be denied because their diagnosis is not one of the select few.

Similarly, a health plan should be expected to provide coverage for treatment of a
diagnosable behavioral health disorder that is seriously disrupting the life of one of its members.

It is important that this Federal legislation be enacted now. Various states, including Pennsylvania, are considering universal health care proposals. Without Federal legislation setting a minimum standard for parity and the treatment of mental health and substance abuse disorders, with a tight budget, states may be tempted to emulate the policies of commercial plans that severely limit such coverage.

The Federal Government has the responsibility to ensure that all its citizens have vital services protected, such as health care, regardless of where someone might live.

Simultaneously, Federal legislation need only establish a reasonable floor and should not preempt State legislation that provides greater protection of coverage for behavioral health disorders. Such is the case, perhaps, with the Pennsylvania ACT 106 for drug and alcohol treatment under commercial insurance.

I do not believe that is your intention, and I heard just that a few minutes ago, that we must sure to protect such state laws, both by making sure
language in the hospital reflects this, and that it is
inserted in any part of the Companion Bill.

The 1999 Surgeon General's report
established that mental health is fundamental to
health and that "Treatment and mental health
services are critical to the nation's health and have
an immense impact on individuals and families
throughout this nation and the world."

Given this, it is time that we make sure
that such services are one of our health priorities
and not afforded second class or worse, no coverage.

Thank you.

(Applause)

MS. BEST: Hello. My name is Kimberly
Best. I am the President Elect of the Pennsylvania
Psychiatric Society, representing over 1,800
psychiatrists practicing throughout the State of
Pennsylvania.

First, I'd like to thank Congressman
Kennedy, Ranstad and Sestak, for scheduling this
important field hearings to promote mental health
parity. My hope is that the 110th Congress will join
the 39 states across the nation that have recognized
the moral and practical reasons for ending the common
practice of making people with mental illness pay more
for their medical treatment than anyone else.

The Pennsylvania Psychiatric Society fully supports Federal legislation requiring health care plans to cover treatment for mental illnesses to the same degree that they cover medical illnesses.

My interest in the issue comes from my work as a psychiatrist, a medical doctor specializing in the treatment of the mentally ill, and specifically, for my work in the Department of Psychiatry at Albert Einstein Medical Center. I am also the Residency Training Director at Einstein, training young psychiatrists.

I treat the full range of psychiatric conditions, and on a regular basis, I see people who've attempted suicide, people who suffer from panic or anxiety attacks, and people who have hallucinations and delusions.

There are some individuals that come into the emergency room for physical symptoms, such as chest pain and difficulty breathing, and after a variety of expensive tests are performed on the patient, they're sent from the emergency room to a psychiatric unit to be treated for anxiety, a very real and destructive condition that falls on the mental side of the spectrum, and therefore, is not
covered as fully as if their symptoms had been caused
by cardiac illness.

I want to depart for a moment from my
prepared comments, and tell you a little bit about
what it's like to actually be a psychiatrist, working
in a system in which there is inadequate mental health
care coverage.

I am board certified in psycho-somatic
medicine, which means that I work with patients who
are both medically ill and mentally ill and I work at
Albert Einstein Medical Center, which is a trauma
center, and at the trauma center, all patients who
come in for a trauma, motor vehicle accident or an act
of violence have alcohol or substance abuses in their
blood, automatically have a psychiatry consult. So,
I've done a great many of these consults over a number
of years and I've become very good at it.

I can work with a patient who has never
previously considered the possibility that they might
have substance abuse, and who when I first meet them,
deny that they, for instance, have a problem with
alcohol, and I'm very, very good at what I do, and I
can bring them, by the end of that interview, to a
position where they're ready and interested in getting
treatment for their substance abuse, and then I go out
and talk to the social worker, and the patient has
grossly inadequate coverage and I know that they're
not going to be able to get appropriate care, of the
kind that I have just convinced them to want, and
that's very frustrating and very discouraging for me,
as a physician and for all of the other physicians
that I work with and train, and many of my residents
are very discouraged about working with patients with
substance abuse, because they know that they're not
going to get the kind of treatment they need and that
their work will be frustrating and I urge you to
obtain parity for us, to do everything that you can,
so that we can do the things that we're trained to do,
that we want to do and we know how to do.

Insurance discrimination against the
mentally ill is an anachronism, a hold-over from the
fifties and we do not really have effective mental
health treatments. We could not just let people who
cannot care for themselves wander the streets, so we
put them into long-term, largely custodial care in
state hospitals. Health insurance didn't cover them
because health insurance was for medical treatment,
and there really wasn't any medical treatment at the
time, so mental illnesses were excluded from coverage,
and that was more than 50 years ago.
Since then, there's been an explosion and
an understanding in mental illness, and it's time for
our attitudes and practices to follow. There is
precedent for making such a change.

It used to be, for example, that syphilis
patients were highest in mental asylums because no one
knew how to treat the disease. Eventually, we
developed an extremely effective treatment and
syphilis is now covered under almost all health care
policies.

It's time for mental illnesses to be
recognized by insurers in the same way. These are the
facts. Mental illnesses are as common, as treatable,
as diagnosable and as subject to biology and genetics
as other health problems. Insurance policies still
discriminate against people with mental illness, as if
it's their own fault that they hear voices that no one
else hears, or that they think they're able to fly
from the tops of buildings, or that their lives are so
full of despair, that they can no longer stand to
live.

Not only is that not true, but it offers
one of the great ironies of the current insurance
situation. Many of the most sacred illnesses, in
regard to health insurance, are medical conditions
that have much more to do with life style choices and behaviors than mental illnesses do.

    Insurers pay huge sums of money for the treatment of such conditions as hyper-tension and diabetes, chronic conditions that are clearly affected by the way the patient lives and eats. Heart disease is another, and what we've learned about cancer, is that it too is often affected by life style and choice.

    Insurance policies cover all sorts of illnesses caused by smoking, so discrimination based on a, "Let them pull themselves up by the boot straps," philosophy is intellectually flawed.

    I want to say a couple of words about the ways in which insurance companies discriminate. The traditional approach to covering mental illnesses has been first, to limit coverage overall. It also tended to offer greater coverage for in-patient than out-patient treatment. This discourages early intervention and actually results in higher use of in-patient benefits.

    That, in turn, perpetuates the myth that mental illnesses are too expensive to treat. This does a terrible dis-service to people.

    Mental illnesses, like others, are very
amenable to early treatment. People should not be constrained by a lack of out-patient care, office visits, because they have inadequate coverage for them. Treating mental illnesses early can and does save money, because it keeps problems from escalating to the point that in-patient care, which is vastly more expensive, is required. It also keeps them from emergency rooms, like our's at Einstein.

In Pennsylvania, the current mandatory minimum mental health care benefits, required by enactment of ACT 150 in 1998, has been helpful in treating mentally ill patients across the state. The implementation of ACT 150 has also assisted greatly when dealing with third party payers, in discussions over the appropriate treatment of patients receiving services in both in-patient and out-patient settings. However, there's more that can be done to ensure that there's equitable coverage for patients that suffer from physical and mental health illnesses.

If there's one idea I can leave you with today, I would like to be that there's no medical justification for the kind of mental health discrimination that currently exists. If health care costs need to be reduced, the job should be done fairly, across the board. It's totally improper for
an enlightened society to manage the cost of treating
the ill by simply eliminating or reducing benefits on
the basis of diagnosis alone.

When you consider Federal legislation of
mental health parity, consider a family with twin
college age sons at home. One has been diagnosed with
diabetes and one has recently been diagnosed with
manic depressive illness. Without treatment for the
rest of his life, the diabetic may go blind, lose a
limb or die early. Without treatment for the rest of
his life, the other may be unable to work and may
become so depressed that he commits suicide or so
manic that he thinks he can fly, and tries to.

You have the power to decide which one of
them will get help. Shouldn't it be both?

(Applause)

CONGRESSMAN KENNEDY: Allen, I first want
to start by mentioning the point that you said about
the section in Pennsylvania law, and the concern that
-- about the preemption.

In our language, in our Bill, we say
{quote} "Nothing in this section shall be construed to
preempt any state law that provides consumer
protections, benefits, methods of access to benefits,
rights or remedies, that are greater than the
protections of benefits, rights or remedies provided
under this section," just to give you some assurance.

MR. HARTL: I believe that's -- I fully
endorse that sort of language, Congressman.

CONGRESSMAN KENNEDY: We're absolutely
right on board with you, and this is very much
different from the Senate, very, very much different
from the Senate. So, I wanted to ask about this
psycho-somatic aspect of the issues that you seek.

When we find that a lot of -- go to the
doctors and complain of irritable bowel or back pains
and so forth, can you describe whether that really is
a manifestation of an untreated psycho-somatic kind of
situation, because of the -- we read this week's
Newsweek, "Men and Depression'. It's the big article
in today's Newsweek magazine, and there's this stigma
behind it.

So, a lot of people go and they complain
of aches and pains that are really, primarily
psychiatric, but come through secondarily as physical.
Could you just describe the phenomena and how you
think it eats up a lot of our health care dollar, in
terms of tests that we do, that we send people for,
MRI's, blood tests, x-rays, and so forth, that may be
really unnecessary, but because we're so obsessed with
MS. BEST: Absolutely. It's often difficult to tell whether something is related to emotions or related to something else. But it's definitely true that anxiety and depression very often show up as physical symptoms, and that patients have repeated laboratory and physical evaluations of those symptoms and don't get a psychiatric evaluation, so that the actual problem that's creating the symptoms, or creating a heightened awareness of physical sensations, doesn't get diagnosed and doesn't get treated. And so, a great deal of resources go to tests that would be needless if they actually got the psychiatric evaluation.

What I think is even more important is that because mental illness is so common and non-mental physical illness is also common, they both often happen together, and when the mental illness is not treated, patients are not able to adhere to the recommendations that their doctors are making, concerning their medical illnesses, so that -- for instance, I consult for the HIV clinic at Einstein, and they very commonly refer patients to me when they're not compliant or not adherent to their treatment regimens, and if I treat their depression or
their anxiety or whatever problem it is that makes them unable to collaborate with their doctors, their health often dramatically improves.

The same is true for diabetes, or for treatment of hypertension. If we can treat the depression and anxiety or schizophrenia or bipolar disorder that these patients also have, then their ability to manage their diabetes dramatically improves.

CONGRESSMAN KENNEDY: If you could do a memo on that. We've got the tag line that says that someone with untreated mental illness has health care costs 100 percent higher than someone with untreated mental illness. The cost of their health care is twice as high, which makes sense. Someone with diabetes who is an alcoholic, imagine trying to treat their diabetes.

MS. BEST: Exactly.

CONGRESSMAN KENNEDY: Someone with depression who has cardiovascular disease, trying to treat their heart disease. We know the correlations here. Someone with asthma, trying to treat them.

So, but if you could, given your anecdotal and particular practice, could give a little anecdotal evidence to that through a memo you could do for us,
that would be very helpful.

MS. BEST: Sure, I can give you some representative examples.

CONGRESSMAN KENNEDY: Perfect, that would be terrific. We have one last couple of folks to speak. Did you have any questions?

CONGRESSMAN SESTAK: If I could. Could I ask, Congressman, your acquiescence and your indulgence. I'm not smart on scheduling Congressional meetings yet, and I have a commitment that I should have left 20 minutes ago for. May I ask your indulgence if I may depart at this time?

CONGRESSMAN KENNEDY: Yes.

CONGRESSMAN SESTAK: Not that this is not probably one of the most meaningful things I've done in the past nine days that I've been home. Is that all right?

CONGRESSMAN KENNEDY: Absolutely. Thank you very much for coming.

(Applause)

CONGRESSMAN SESTAK: Thank you.

CONGRESSMAN KENNEDY: This is the benefit where if you've been in office for 12 years, you have all the time in the world, because when you're in your first term, you've got to keep running. Thank you,
Joe. Let's hear it again for Joe, for a great job.

    (Applause)

CONGRESSMAN KENNEDY: If Steve Winter could come up too. Steve, could you come up?

MR. SARNESO: My name is Mark Sarneso and I am Chairman of DASPOP, which is the Drug and Alcohol Service Providers Organization of Pennsylvania, as well as working for CRC, which is the largest addiction treatment system in the country. I'll just make my comments very brief on behalf of DASPOP and CRC.

First of all, Representative Kennedy, we really thank you for your efforts on this. In addition, many people in the room probably do not understand the amount of feedback you have asked for, and have received and have listened to, in terms of our concerns about really, the devil being in the details about this piece of legislation, and it really is a democracy in action, and for somebody that's somewhat cynical about it, I really applaud you for your efforts on that. Thank you.

I guess I'm just here just to caution about the law of unintended consequences. I think you're getting the sense, Congressman Kennedy, that in Pennsylvania, we love our ACT 106, and we don't want
anything to happen to ACT 106. So, thank you.

The other thing I would just ask is, I'm a little concerned about the two-prong strategy, in terms of getting this Bill done and then following it up quickly thereafter with a Patient Bill of Rights.

If you win the first one and don't win the second one, then what we've done is kind of Federalized managed care, making some clinical decisions on behalf of our patients, and I'm really concerned about that.

So, that would be my other concern, that we do not give statutory basis to managed care. We do not Federalize or nationalize the ability of managed care to make clinical decisions in lieu of doctors, psychologists and counselors.

So, again, we keep knocking on your door and asking you to take a look at these issues, and we do appreciate, so much, your perseverance with us and listening to us, but these are just such critical decisions.

I don't know what's more frustrating, not having the access to the benefit or having the benefit and not being able to access it. It really -- it is so frustrating for folks who say, "But I had this benefit policy that says 30 days. Why is my insurance
company giving me two days?"

I just would like to raise those issues, and again, you've been great in listening to the field. So, thank you very much.

CONGRESSMAN KENNEDY: Thank you on the point that you made. I want to understand what you're saying about the Patient's Bill, because I don't know how it can get much worse than it is now, in terms of managed care. What are we -- because where we're right now, it's -- we don't have any Patient's Bill of Rights now.

MR. SARNESO: Right, we don't, but the language of the Bills, in particular, I guess, I probably should say the Senate Bill, but the language of the Bills does -- it gives the benefit.

For example, the Federal Employee Benefit Health Plan, it gives parity, but in order to access the benefit, you have to go through a managed care gate keeper, and there is where you get the obstacles and that's when you talk to a doctor, `1-800-KNOW'.

What I'm concerned about, a national law would then in-bold in that, so that those practices that are very difficult to begin with now, they become part of law. If you can't then, follow it up with a Patient's Bill of Rights, then we are working under
legislation or a law that recognizes the parity, but then turns the most important decision, how much treatment and the level of intensity of treatment, over to a third party administrator or managed care provider. That would be very difficult.

Would it be any better than it is now? Maybe not. Would it nationalize it? Would it give statutory base to those practices? I think it would.

Again, I may be wrong. I'm just concerned about the law of unintended consequences.

CONGRESSMAN KENNEDY: Yes, I think that it's hard to get much worse, I mean, $60 billion in profits for United Health, just last quarter alone.

MR. SARNESO: And those are the -- those are on the backs of people who pay premiums, that don't get treatment.

CONGRESSMAN KENNEDY: That's right. Steve, if you could explain -- talk, first about how you came -- how we first met, about the issue of the catheter, the issue that you brought to my attention, and then we got talking about that, and then your own personal story, which is what led you here today, to testify, and I'm glad that you were able to.

The irony is that, I first met with Steve about an unrelated issue to mental health. But it was
related to insurance, and it's a particular poignancy to -- and it's very analogous to this issue of discrimination and insurance, and then he told me his personal story, which has a great deal of residence to all of us, with respect to mental illness.

So, I was very happy he could come here today to testify.

MR. WINTER: I want to first thank Debbie from your group. I have quite an adventure getting here. It's kind of hard to sit in the Arizona Airport on Sunday, give you sunburn from the window, and then they tell you your flight is cancelled due to weather. But there is East Coast. I missed the Trenton, I apologize.

Today, my hotel told me Elwyn is right across the street. So, I started wheeling down the street. It's not quite across the street. So, the cars as whizzing by and at about a mile and a half down, Debbie picked me up and brought me here. Otherwise, I don't know what would have happened, but I'm glad to be here.

One point I want to make is that -- it's just like -- I don't want to say the insurance companies are like robbers. They're always ahead of the game, more than the criminal.
The insurance companies are way ahead of you right now. They already have their own Parity Bill. They're starting to bring down physical illness payments down to mental illness payments.

At first, I thought it was self-serving, but it is the ultimate example of what they're doing. They're cherry-picking high, expensive diagnosis and just going after them. And the issue I came to with Congressmen Kennedy was, for spinal cord injuries, MS and spina-bifida, no doctor would disagree that using urinary catheters is a medical necessity. You'll die. There's no dispute over that.

But someone mentioned that the insurance companies are breaking the law. Well, CMS itself is breaking the FDA law. They turn all their payments over to four doctors who don't practice medicine and private insurance companies can make all the Medicaid work policies. What's good for them, is if they make the policy for Medicare, then when they -- the person has private insurance, Medicare doesn't pay for it either.

Well, in their great wisdom, 10 years ago, they made a policy where a urinary catheter, you go in and out six times. It's a single use item only. Well, why don't you wash it with soap and water and
reuse it, and we'll only give it -- pay for the catheters, how they're suppose to be paid for in the first place. If you get two urinary tract infections with specifically, 100.9 degree temperature. So, if you have 100.8, the doctors says, "Well, let's not take you in a box until we get you up to 101."

What I tell people in all the health care -- because it's going across the board, physicians, providers, if they're not going to pay for catheters, they're not going to pay for mental health. They're even doing policies now where we don't cover catheters. It's like they're paying for everything -- if you have an HMO, they work until you have to use it.

How I met Congressman Kennedy was through that issue and for a personal issue, this mental health touches my heart personally. Every day for the rest of my life, I wake up and I know the shortcomings of the mental health system.

I grew up in Akron, Ohio, Ozzie and Harriet neighborhood. You wake up, you think Ohio State football your whole life. That's all, normal childhood.

Well, one day on December 28th at about 7:00 a.m., I'll never forget this day, I was getting
ready to go to basketball practice for high school. We were on Christmas break. I had to walk a couple of miles in the cold weather. I was eating a bowl of cereal and just -- all the sudden -- I was kind of a momma's boy, and I -- my mom just yelled across the room. It felt different. Something was wrong. I couldn't figure it out. No pain or nothing. Kept eating my cereal.

Again, I yelled, "I don't know what's wrong with me, but something is wrong." I couldn't figure it out. All the sudden I reached down in my shirt and I had a handful of blood. So, then my mom came in and she had a gun in her hand and she goes, "Steve, I shot your sister. I shot you and I'm going to shoot me so we can be in heaven together."

I go, "Mom, you need to put the gun down."

We didn't have `911' back then. I go and call the ambulance over and over again. Put the gun down. She did and then finally, the police came and she was fine. I'll never forget that ambulance ride there, because in the movies you see those -- you see the breath and all the sudden it stops. You think, "Am I going to make it or not?" I have no idea.

Well, luckily it didn't hit organs. Unluckily, it hit my spinal cord, and I'll be a spinal...
cord injury for the rest of my life.

Like he was saying, at these emergency room visits, my bills are probably a million and a half dollars or two million. All because of the breakdown of the mental health system.

Once my mom got the treatment she deserved -- the Court did not put her in prison. Put her for nine months. She got back, nothing, no problems since then.

Why did it take me being in a wheelchair and -- I'm not a professional victim. These are all facts.

These insurance companies, they paid -- look at Aetna is paying for all my bills now. I don't know why they don't get it. It's just -- but I do.

One fact I had to say though, it would have to be legislated, because I'm not going to be judgmental. If I'm a CEO of Aetna or some of these insurance companies, maybe if I saw billions coming by, I wouldn't have the self-control.

These personal stories, let's do it for them. Let's legislate it for the insurance companies, because he may have to answer to his Board of Directors. Maybe -- I'm not going to again -- maybe they want to pay for this stuff.
So, let's do it for the insurance company executives, so they can say to the Board of Directors, "You know what? We have to pay for it. Now, we're going to make $30 billion this quarter, instead of $60 billion."

(Applause)

CONGRESSMAN KENNEDY: Steve actually hit it on the head with the -- with the TB.

MR. WINTER: Oh yes, he's probably getting used to all the boring stories, but yet, the ones -- there is a stigma about all illnesses, but -- we can't hide behind -- I don't know anything about this 12 step program, but I think the insurance companies put the 11th step in, "Don't bring it out in the public."

It doesn't make sense. Just like with a spinal cord injury, some people say when you first get hurt, "You don't want people to feel sorry for you," but how does a Congressman know you want spinal cord research? The only thing they see is a guy climbing a mountain with a wheelchair.

The stigma about mentally ill patients not treated, are dangerous to themselves and to other people. That's a fact. It's not a stigma. But so is, if I was on a plane going home, and two people are coughing next to me, if I say, "He has a pretty bad
cold," and they say, "No, we have tuberculosis. My insurance company doesn't pay for it." They're dangerous. I'm more nervous with them.

A case that was brought up when -- a trial back in Ohio was, a diabetic patient went into a coma, because it was untreated, and -- in California, he drove in and killed a family.

Again, any untreated physical illness is a danger to them selves and to other people. If I told you I had the Bird Flu right now, would you guys be running out? It's just ridiculous, and for me, I have no patience. My wife says I'm too blunt. But this is ridiculous.

If I had the insurance company guy, "Why are you not paying for it?" When you have a ridiculous statement, they throw red herrings out there for ever. But let's start asking them the questions.

I think it might help -- it's helped with the catheters, if -- the initial thing is, when your insurance company says, "The patient is fine. They can leave. They are no danger," get a letter from them saying, "Well, we have medically said there are no problems and they can leave early and they'll be no danger to anybody else," and they'll give you another
week, because they don't want the liability.

CONGRESSMAN KENNEDY: That's what we're going to do, make them liable, as much as the doctor that is actually right now. If once you put the liability on those bean counters insurance, accountants, who are the ones that are telling people that they should leave, and put it on them now, that's when you're going to start to change the dynamics.

MR. WINTER: I was excited when you said that you're doing the follow up too, because they want to -- if they diagnose -- if the insurance company is giving the criteria to pay for mental health bill, the would be the criteria, it is you have to commit suicide twice before you get your insurance payments paid for.

So, I want you to do that, just like you're -- when I first called the FDA on my case -- and FDA is 100 percent behind me, they thought -- the FDA thought I was a little -- you guys get calls and think, "Who is this guy?" When I told them the policy of CMS of reusing catheters, and they -- FDA did a big thing on reusing medical products and they said, "When it's all said and done, they have to be reprocessed the same way a hospital does."

So, I called them up and say, "Well, that'
crazy. It would cost more money to send the catheter back to the reprocessing plant, than to" -- they're saying use soap and water and put it in a baggie. I don't think Glad baggies are a sophisticated medical device carrier.

It's really ridiculous. That's all I can say.

CONGRESSMAN KENNEDY: Well, Steve, you made the point, so powerfully, and you all know why we're here then and what we're up against. Mental Health American has started a citizens petition on-line, so that all of you can now be citizen co-sponsors of this legislation, and in addition to that, you ought to sign up, because we've got a broader agenda, as I said.

The only way this is going to happen is, politically, we have to get engaged, and the only reason none of this has happened so far is mental health, because it's been so stigmatized politically, when it comes to mental health week, no one is in the hallways, because we're all so -- as consumers, we're all so in the shadows.

So, this is going to change. It is changing. Your being here today proves that. So, stay involved. Tell your friends and family members
to keep coming out and calling your members of Congress, call your Senators and make sure that the strongest Bill possible comes out of Congress, and to protect the people and make sure that we end discrimination.

Thank you, all of you, for coming out today. Thank you.

(Whereupon, the foregoing matter concluded at approximately 11:10 a.m.)