``DOES HIPAA HELP OR HINDER PATIENT CARE AND PUBLIC SAFETY?''

FRIDAY, APRIL 26, 2013

House of Representatives,

Subcommittee on Oversight and Investigations

Committee on Energy and Commerce

Washington, D.C.
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Mr. {Murphy.} Good morning. We are here today, the Oversight and Investigation Subcommittee of Energy and Commerce, for a hearing entitled, "Does HIPAA Help or Hinder Patient Care and Public Safety?'"

As there is a classified briefing as well as votes this morning, we are going to waive opening statements in order to get right to the witness testimony. We will allow members to submit their opening testimony for the record.

A hearing last month addressed issues raised after the Newtown tragedy, some of the witnesses told the subcommittee how HIPAA had hindered their ability to care and treat for loved ones. We are going to hear from a number of folks, government representatives, professionals, parents, experts, family members. It is an important issue.

Members, the reason we are here is members of Congress themselves are experts and knowledgeable on many of these issues, so we appreciate your attention to this. We are here to ask questions and learn the facts about HIPAA from those who are knowledgeable of them and remind everyone that we need to maintain decorum in the committee room. Disruptions

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will not be tolerated and people doing so will be discharged if needed.

We also are asking members stick closely to the time limit as we go through.

Ms. {DeGette.} Will the Chairman yield just briefly?
Mr. {Murphy.} Yes. I yield briefly.

Ms. {DeGette.} The Chairman and I have agreed to put all of the opening statements in the record, and I think that is appropriate given this classified briefing which was just scheduled yesterday out of respect to the witnesses, many whom have come from around the country. The Chairman and I decided we really wanted to hear from the witnesses.

I will say, Mr. Chairman, though, that this is really an important topic, the HIPAA issues, particularly as they relate to gun violence, but it is also important if we are being asked to get the U.S. militarily or otherwise involved in Syria and this classified briefing is with the Secretary of State, so on behalf of everybody I want to apologize to the witnesses. Some of us may be coming in and out, but we will read the testimony, and we will make sure we know what is going on.
So thank you very much, Mr. Chairman.

Mr. {Murphy.} I appreciate it. I want to also let members know I communicated with Majority Leader Eric Cantor last evening, and he is having his staff working on providing a special briefing for any members who remain through this committee.

You are aware that the committee is holding an investigative hearing. I say this to the witnesses, Mr. Rodriguez and Mr. Rothstein, and when doing so, we have the practice of taking testimony under oath. Do you have any objections to testifying under oath?

Thank you.

The Chair then advises you that under the rules of the House and the rules of the committee you are entitled to be advised by counsel. Do you desire to be advised by counsel during your testimony today?

Thank you.

In that case will you please rise and raise your right hand? I will swear you in.

[Witnesses sworn]

Mr. {Murphy.} Let the record show the witnesses have
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answered in the affirmative. You are now under oath and
subject to the penalties set forth in Title XVIII, Section
1001 of the United States Code. You may each now give a 5-
minute opening statement, but let me introduce the witnesses
for today’s hearing.

On the first panel we have Mr. Leon Rodriguez. Mr.
Rodriguez is the Director of the Office for Civil Rights at
the Department of Health and Human Services. He oversees the
administrative operations of the civil rights division.

We also have Professor Mark Rothstein. He has a joint
appointment at the University of Louisville, School of Law,
and the School of Medicine. He also holds a Herbert F. Boehl
Chair of Law and Medicine and is the founding director of the
Institute for Bioethics, Health Policy, and Law at the
University of Louisville School of Medicine.

Gentlemen, you may begin. Make sure your microphone is
on and pulled close to your mouth. Thank you. You may
begin.
Mr. {Rodriguez.} Good morning, Mr. Chairman, Ranking Member DeGette, and members of the subcommittee. It is an honor for me to be here today in my capacity as Director of the Office for Civil Rights at the U.S. Department of Health and Human Services, and I thank you for calling a hearing on this very important topic.

As HHS's enforcement agency for civil rights and health privacy rights, OCR handles enforcement policy, development in education for compliance of laws in those areas. Our office plays an important role in ensuring that an individual’s sensitive health information remains private and secure and that individuals are able to exercise important
rights with respect to their health information.

One of the underpinnings of HIPAA is that optimal healthcare depends for many patients on their trust that their health information remains confidential. HIPAA also ensures that health information can flow for important and necessary purposes such as patient treatment, obtaining treatment for health services and protecting the country’s public health and safety. I have often said that HIPAA is meant to be a valve and not a blockage, and that it is above all meant to maximize the welfare and interests of the patients.

As such I look forward to discussing the existing flexibilities within HIPAA. HIPAA recognizes the vital role that family members play in supporting patients with significant illness, both physical and mental. I have read the family testimonies that were placed in the record and are heartbroken by them, and so, therefore, take seriously this committee’s desire to get to the right answer on these issues.

To directly address the concerns that underlie in this hearing I will discuss the paths that HIPAA offers for
providers to disclose information received during treatment to protect the health and safety of other patients. For example, HIPAA permits personal health information to be used or disclosed without an individual’s authorization for health treatment and payment and for the business operations of covered entities. HIPAA also permits other uses and disclosures for certain public health activities, for law enforcement purposes, and to avert serious and imminent threats to health or safety.

I would like to talk about disclosures to family members and friends of patients. This is an important area. Ordinarily if a patient does not object to information being either shared in front of family members or friends or with family members or friends, HIPAA provides a clear avenue for disclosure in those cases.

Additionally, if a patient is incapacitated, and when I say incapacitated, we mean for that word to be given its full ordinary meaning. Healthcares may still communicate with family and friends of the patients if the provider determines based on their professional judgment that doing so is in the best interest of the individual. And this is, I think, an
important point to underscore. HIPAA is meant to revolve
around the professional judgment of the provider as to what
is the in best interest of the patient. It is not meant to
supplant that judgment.

And so, for example, a nurse can discuss a patient’s
medical condition in front of the patient’s sister, who
accompanies them to appointment. If a patient is unconscious
or otherwise incapacitated, the doctor, again, can make that
judgment to share information with family members.

Similarly, HIPAA recognizes that professional codes,
state laws, professional standards of care recognize a duty
and authority to warn of situations where a patient may pose
a danger to themselves or others or may have disclosed
information indicating a threat by another to either
themselves or a third person.

In those cases where there is a serious and imminent
risk of harm to health or safety, HIPAA has a clearly-
recognized exception for disclosure in those cases. And when
I say an imminent risk to health or safety, it is not simply
the scenario of an individual going out to commit a violent
crime, but, in fact, it covers a number of possible scenarios
196 that a healthcare provider, particularly a mental healthcare
197 provider, may encounter.
198 We take our obligations to educate providers and
199 patients on these flexibilities seriously, and it is for this
200 reason that we and the Administration took the initiative in
201 January after the tragic events in Newtown to issue a letter
202 to the Nation’s healthcare providers clarifying these
203 important points.
204 Finally, I want to talk for just a moment about the
205 nature in which we utilize our enforcement authorities. We
206 focus primarily on longstanding broad-based security threats.
207 We have never taken enforcement action because a provider has
208 decided in the best interests of a patient to disclose
209 information to a third party.
210 Thank you, Mr. Chairman, thank you, Ranking Member,
211 thank you, members of the committee.
212 [The prepared statement of Mr. Rodriquez follows:]

213 **************** INSERT 1 ****************
Mr. {Murphy.}  Thank you, Mr. Rodriguez.

Mr. Rothstein, you are recognized for 5 minutes.
TESTIMONY OF MARK A. ROTHSTEIN

Mr. {Rothstein.} Mr. Chairman.

Mr. {Murphy.} Pull the microphone close to you, if you would.

Mr. {Rothstein.} Mr. Chairman.

Mr. {Murphy.} Still not on. Is it on? Pull it real close.

Mr. {Rothstein.} Okay. How about there?

Mr. {Murphy.} There we go.

Mr. {Rothstein.} Thank you.

Mr. {Murphy.} These are government mikes so during the sequester they are down 20 percent.

Mr. {Rothstein.} As is my voice, I am afraid.

Mr. Chairman and members of the subcommittee, my name is Mark Rothstein. I am on faculty of the University of Louisville, but I am testifying today in my individual capacity, and, again, let me apologize for my laryngitis. It is seasonal I am afraid.

In my testimony this morning I want to make the
following three points. First, the HIPAA privacy rule is essential to patient care and public health and safety, second, exceptions to the privacy rule permit disclosure of health information for important public purposes, and third, additional measures could enhance the effectiveness of the privacy rule.

First, ever since the Hippocratic Oath, medical codes of ethics have established the duty of physicians to maintain the confidentiality of patient health information. Without assurances of confidentiality, patients will be reluctant to divulge sensitive information about their physical and mental health, their behavior, and lifestyle that could be vital to the individual’s treatment. The privacy rule codifies this crucial requirement of confidentiality which is necessary for ethical and effective individual healthcare.

Health privacy laws also are essential to the protection of public health and safety. To illustrate, this afternoon I will be returning home to Louisville. At lunch, I did not want my cook or server to be someone who was reluctant to get treatment for hepatitis A because of privacy concerns. I do not want as my taxi driver someone with chronic tuberculosis
who was afraid to get ongoing health treatment. I do not want my flight safety placed at risk by an air traffic controller with a mental health problem or a pilot with substance abuse who was deterred from obtaining behavioral health care. Confidentiality protections, therefore, serve to advance both the patient’s and the public’s interest. Although we were all deeply saddened by the recent horrific loss of life caused by some violent, mentally-unstable individuals, we should appreciate the potential consequences if new, excessive mental health reporting requirements were enacted. Each year in the United States there are over 38,000 suicides and over 700,000 emergency room visits caused by self-inflicted harms. An estimated 26.2 percent of the people in the U.S. have a diagnosed mental disorder in any given year. Any steps to lessen confidentiality protections or mandate the unnecessary disclosure of mental health information could lead vast numbers of individuals to forego mental health treatment and potentially result in significantly more suicides, self-inflicted harms, and untreated mental illness.

Second, the privacy rule specifically permits a covered
entity to disclose 12 types of health information of importance to the public, and therefore, the privacy rule does not hinder public safety. Among these 12 categories are disclosures for public health activities, about victims of abuse, neglect, or domestic violence, for law enforcement, and to avert a serious threat to health or safety.

The 12 public purpose exceptions are permissive. The privacy rule does not require any disclosures. The disclosure obligations arise from other sources such as state public health reporting laws. The effect of the public purpose exceptions is to permit otherwise-required disclosures without violating the Privacy Rule.

Third, for the last 10 years, inadequate health professional and patient outreach and education programs have led to a lack of understanding of the privacy rule by many affected individuals and covered entities. A common problem is that some uses and disclosures permitted by the privacy rule are not allowed by some covered entities, perhaps out of ignorance or an over-abundance of caution.

The 2013 promulgation of the omnibus amendments to the privacy rule make it an appropriate time for HHS to start a
In conclusion, the privacy rule, I believe, is essential to individual healthcare and public health and safety. Additional efforts to increase understanding of the privacy rule by the public and covered entities, as well as revising some of the public purpose exceptions, will enhance the effectiveness of the privacy rule.

I thank you for the opportunity to testify this morning.

[The prepared statement of Mr. Rothstein follows:]
Mr. {Murphy.} I thank both the gentlemen. Let me just ask some questions. I recognize myself for 5 minutes.

During this subcommittee’s March 5 forum we had on severe mental illness, Pat Milam, father of a son with a serious mental illness, pointed to HIPAA as a significant obstacle to getting his son the help he needed. Mr. Milam explained that one of his son’s doctors judged him to be, "of extremely high risk for suicide with a bad outcome," more than once and yet failed to share this information with Pat or his wife. Matthew Milam tragically took his own life only months later while living with his parents, and it was only after Matthew’s death that the Milams were able to obtain their son’s medical records.

Is this an example where HIPAA worked as intended, Mr. Rothstein?

Mr. {Rothstein.} No, but if HIPAA were followed to the letter, that would have permitted the disclosure under--

Mr. {Murphy.} Mr. Rodriguez, you agree with that, too? Does HIPAA bar a physician or a licensed provider from revealing health information to the parents of a young adult
who is living with their parents? Yes or no, Mr. Rodriguez?

Mr. {Rothstein.} No.

Mr. {Rodriguez.} Under some circumstances it might. In most circumstances there would be paths for disclosures to those parents.

Mr. {Murphy.} Paths for disclosure. Does it allow physicians to provide information to parents if the young adult is receiving care through the parent’s healthcare plan up to age 26 as envisioned by the Affordable Care Act? So if they are still dependents, or is it an age? Can you tell me where that cutoff is?

Mr. {Rodriguez.} Yeah. The cutoff in terms of the patient’s ordinary ability to object to the provider’s disclosure is the age of majority, whatever it happens to be in a particular State.

Mr. {Murphy.} So in Pennsylvania it is age 14. A 14-year-old could decide whether or not that information is to be disclosed. In other States it may be 18.

Mr. {Rodriguez.} Yeah. I would assume ordinarily it would be 18.

Mr. {Murphy.} Are either of you familiar with the term,
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anosognosia, what that term means?

Mr. {Rodriguez.} I am aware of it, Chairman, because I actually read the majority memorandum for this hearing. Certainly going back to the discussion of serious incapacity and the discussion of serious and imminent risk of harm, certainly situations where that condition either renders the patient to be in a condition of incapacity or where the consequences of that condition being unaddressed are a serious risk of imminent harm to health or safety, again, it doesn’t mean going out and committing a gun crime. It can mean a variety of different things that could be extremely harmful to that patient.

Then, yes, in those cases a patient could disclose without consent.

Mr. {Murphy.} Mr. Rothstein, would you agree?

Mr. {Rothstein.} I agree. Yes.

Mr. {Murphy.} It sounds like from what I read from your testimony and what you have said here that we may find that a lot of providers are misinterpreting or over-interpreting the laws on HIPAA which prevent them from disclosing things to patients. Is that what you are suggesting is happening here?
Mr. {Rodriguez.} Chairman, we have observed in a variety of our areas of enforcement that there is anxiety about our rules in all the wrong places. If you look at where we have taken enforcement action, it has been focused on institutions that have had longstanding failures to protect the security of all of their patients’ information. HIPAA was designed to respect the provider’s judgment as to their patients’ best interests. I think that is often, unfortunately, misunderstood, and that is one of the reasons we put that clarification.

Mr. {Murphy.} Let me ask this because gets to the crux of the matter of why we are here today, and we are going to hear some testimony from some professionals, some experts, and some parents.

What if the provider decides not to share the memo or the information, whatever, for those reasons? What is the patient doesn’t sign a release? A patient themselves does not even recognize they have a problem, and the parents even go to court and say, we would like to have these records reviewed. In some cases the hospital staff says, I can’t release these records if a Judge says we can, and the Judge
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asks the patient, the patient says, no, and yet a condition may still exist that that patient is at risk for suicide or harm to themselves or not following their treatment. What then?

Mr. {Rodriguez.} One thing to also keep in mind in answering this question is HIPAA’s not the only relevant body of law. So we are also talking about professional ethical standards, both the American Psychiatric Association, the American Psychological Association imposed clear duties of confidentiality and create exceptions as we do, and, in fact, our rules are built around both those ethical duties and State law duties such as, for example, that in the Tarasoff v. California Board of Regents case. Clearly in the kinds of scenarios where you describe where a provider is aware, for example, the risk of suicide, a very clear situation where we are talking about serious risk of imminent harm, HIPAA does not stand as a barrier, even in the absence of the patient’s consent to disclosure.

Mr. {Murphy.} I am going to cut myself--

Mr. {Rodriguez.} Anybody who can help the patient.

That is a critical element here. To that person who can
Mr. {Rodriguez.} Thank you. I am out of time. I am going to go now to Ms. DeGette for 5 minutes.

Ms. {DeGette.} Thank you, Mr. Chairman.

I think we can all agree that HIPAA provides many important protections for people’s medical privacy, and we have a history of bipartisan agreement that people need to be able to keep their sensitive health information private, and so I think we would agree with our witnesses on the importance of HIPAA but also we need to recognize that in many of these mass shootings that we have seen and in many mental illness situations where someone is a risk to themselves and to their families, there are clearly some problems with how providers and institutions are interpreting HIPAA obligations. Because it seems to me if someone is a danger to themselves or to others, that would be up to the provider’s decision to advise the parents or other responsible adults.

Is that correct, Mr. Rodriguez?

Mr. {Rodriguez.} Yes. It would--
Ms. {DeGette.} And Mr. Rothstein, is that correct?

Mr. {Rothstein.} Yes. I agree with that.

Ms. {DeGette.} So I just want to say I am not going to blindly defend HIPAA, but I think we should be very, very careful when we contemplate changes to that statute. We heard in March about providers’ interpretations of HIPAA and how they can be barriers to treating not just the mentally but also the physically ill.

I myself, as a parent, I have a diabetic child, and even before she was 18 years old sometimes we had a hard time getting providers to give us information. That is not because of HIPAA. It is because the providers misinterpreted HIPAA, and so when we hear these tragic stories today, and I am hoping I will get back for that, I think that we need to really take that seriously, but we need to look at ways to educate providers.

In the aftermath of the murder of 32 people at Virginia Tech we learned that HIPAA interpretations prevented mental health professionals from appropriately sharing information. Misinterpretations of HIPAA and other private laws were also identified by the GAO and by President Obama’s Gun Violence...
Task Force as an obstacle to reporting individuals who should be barred from gun ownership to the next background check system.

And so, Mr. Rodriguez, I think you would say HHS has tried to be responsive to these concerns that interpretations of HIPAA and other privacy rules have created obstacles. Is that correct?

Mr. {Rodriguez.} That is correct. That is why we--

Ms. {DeGette.} And, in fact, you sent a letter out on January 15 of this year to health providers around the country, trying to delineate exactly what HIPAA says.

Correct?

Mr. {Rodriguez.} Yes, we did.

Ms. {DeGette.} Now, tell us why you sent this letter.

Mr. {Rodriguez.} We thought that because of all the concerns about the interaction between situations where a provider is aware of information indicating danger to either patient or others and some of the events that we have been hearing about in recent years, that it was important to remind providers of the--of both the duty, the permissions under HIPAA but also to remind them to consult with their
applicable ethical standards and their applicable State laws
clearly do give them a pathway to report in these kinds
of situations.

Ms. {DeGette.} Thank you, and HHS recently issued an
advanced notice of proposed rulemaking to solicit public
comments on HIPAA and its perceived barriers to the reporting
of individuals to NICS due to mental health concerns. Is
that correct?

Mr. {Rodriguez.} That is correct.

Ms. {DeGette.} And can you explain very briefly why
this advanced notice of rulemaking is necessary and what
information you are trying to collect?

Mr. {Rodriguez.} Sure. In most States reporting as to
disqualifying information for NICS actually comes from the
judicial system, which is not covered under HIPAA. We are
aware at least generically about some examples. New York
State until recently was one very clear example of States
where reporting occurred from entities that are, in fact,
covered by HIPAA, and reporting would ordinarily have been
prohibited by HIPAA. We want to understand where and to what
extent HIPAA is a barrier in those cases and take any
appropriate steps to--

Ms. {DeGette.} Thank you.

Mr. {Rodriguez.} --remove those barriers.

Ms. {DeGette.} Okay. Just one last question.

Now, the Affordable Care Act, it extended insurance to

dependents up to the age of 26. Correct? Yes or no?

Mr. {Rodriguez.} That is correct.

Ms. {DeGette.} Yes, but it didn’t say that individuals

up to the age of 26--maybe that this a good question for you,

Mr. Rothstein. It didn’t say individuals up to an age of 26

were still considered legally dependents of their parents

because they are getting health insurance. Is that correct?

Mr. {Rothstein.} Yes.

Ms. {DeGette.} And, in fact, the provision of the

Affordable Care Act didn’t even talk about HIPAA, did it?

Mr. {Rothstein.} Correct.

Ms. {DeGette.} That is correct. Okay. Thank you.

Mr. Chairman, I would ask unanimous consent to put this

January 15, 2013, letter from the Director to providers into

the record.

Mr. {Murphy.} Without objection we will--
Ms. {DeGette.} Thank you very much.

[The information follows:]

*************** COMMITTEE INSERT ***************
Mr. {Murphy.} Thank you. The gentlewoman’s time has expired.

I now recognize Dr. Gingrey from Georgia for 5 minutes.

Dr. {Gingrey.} Mr. Chairman, thank you, and thank you very much for calling this very important hearing. You know, I am sitting here thinking as a physician member of the subcommittee that it is kind of ironic, isn’t it, that this law passed in 1996, HIPAA. It almost sounds like the Hippocratic Oath, which, of course, in the first place, do no harm. It really in a way has nothing to do with the Hippocratic Oath, which is hundreds, if not thousands, of years old, but in a way it does touch on that in the first place, do no harm, in regard to how you treat a patient but also this information sharing because if it is not done correctly, great harm, there is potential for great harm, not only for the patient but to the general public. So I just think that I find that sort of ironic.

Mr. Rodriguez, when was the last time that the Office of Civil Rights under HHS updated the Healthcare Provider’s Guide to the HIPAA Privacy Rule posted to the OCR website?
And how about the Patients’ Guide? Same thing.

Mr. {Rodriguez.} Congressman, Doctor, we are updating on a routine basis as different issues comes up. As you know, we issued a major rule that profoundly affects both consumers and providers in January of this year, and so we have been busy posting updates relevant to that rule.

Dr. {Gingrey.} That was that January 25 rule?

Mr. {Rodriguez.} That is correct. Similarly, when we identified the concerns about gun violence after the Newtown shooting, we took immediate and decisive steps to put up this reminder about the manner in which HIPAA interacts with the duties. We are updating our information on a very--

Dr. {Gingrey.} Well, these guides answer common questions about HIPAA. Correct?

Mr. {Rodriguez.} That is correct.

Dr. {Gingrey.} And do you ever receive input from either the general public or the healthcare providers about the effectiveness of these updates?

Mr. {Rodriguez.} We do. We speak routinely to both consumer groups and provider groups. My door is always open.

In fact, I took the initiative this morning to connect with
several of the family members here today because I want to hear from them. I want to know these concerns and make sure that we are getting--

Dr. {Gingrey.} I am going to come right back to you, but Mr. Rothstein, are you familiar with these guides? Do you have any sense of how effective they are?

Mr. {Rothstein.} Well, I am not sure how effective they are, but I can comment generally about the Outreach in Education Program and with all due respect to OCR and HHS, I think we have a major problem in this area. If you read the regulations, there are ample places where these kinds of issues, the problem of notifying parents, the problem of notifying individuals who are at risk, is spelled out. But HIPAA is a very misunderstood regulation. It is misunderstood by the public, it is misunderstood by healthcare providers and--

Dr. {Gingrey.} Well, let me interrupt you to say that I fully agree with you, and as a practicing physician for a long time before I come here 10 years ago, I knew that, and I think, in fact, I wonder if some physicians don’t hide behind if I just move onto the patient, not want to be bothered with
an aunt or an uncle or a cousin, you know, in regard to questions about their loved one. I hope that doesn’t exist too much, but, I mean, it is something that we need to think about.

Let me go back to the Director of the Office of Civil Rights, Mr. Rodriguez. How does OCR measure? Now, I think when I was talking to you just a second ago, it sounded like it was more anecdotal from your perspective, but how does OCR measure whether the clarifications that you referenced January 25 of this year, indeed, how do you measure how they are working? For example, have the number of privacy rule complaints filed under the various complaint categories been trended downwards with every further clarification, hopefully this most recent one from OCR? Does OCR keep track of this? Do you think this will be a helpful metric to track in judging the performance, your performance of your outreach and education efforts concerning the privacy rule?

Mr. {Rodriguez.} So answering the first part of your question, Congressman, the truth is our caseload has remained steady, and in fact, has grown slightly over the years since we commenced enforcement. We received something in the order
of I think approximately 80,000 complaints since we first began receiving, and the amount is fairly steady over the years.

Part of what is going on here is HIPAA’s still, you referenced 1996, but our rules really didn’t become final until 2003 and 2005. And so there has been a learning curve over the years both for consumers and providers to understand what HIPAA requires and what it authorizes, and we often emphasize that HIPAA’s flexible and scalable, meaning that it is really meant to be designed for a very wide variety of healthcare scenarios.

I agree generally that our caseload is certainly an indicator. I don’t think it is the only indicator of how well folks are understanding the requirements. I certainly agree with that proposition. I think there have been surveys. I am not able to speak to them specifically right now in terms of where patient concerns are, where provider concerns are, but we certainly do hear a lot of anecdotal information as you described.

Dr. {Gingrey.} Mr. Chairman, thank you for allowing the witnesses to answer, and I yield back.
Mr. {Murphy.} Thank you.

Dr. {Gingrey.} Thank you both.

Mr. {Murphy.} I now recognize the gentleman from Iowa, Mr. Braley, for 5 minutes.

Mr. {Braley.} Thank you, Mr. Chairman, for holding this very important hearing which deals with the ongoing struggle between patient privacy and protecting the public safety, and these are not easy issues to deal with, but I think part of the challenges we faced and part of the concerns of family members who have been dramatically impacted by our inability to solve this problem is that these particular provisions you have been talking about, Mr. Rodriguez, are commonly known at the Duty to Warn Provisions, and yet to most of us who understand duty to warn, a duty is a mandatory obligation, not a permissive requirement. And even though I understand completely your explanation of how this permissive disclosure is then subject to State laws dealing with mandatory disclosure, I think many healthcare professionals, particularly mental healthcare professionals, look at the HIPAA language, see that it is permissive, and that is the end of the story for them.
And I would like to hear from both of you how are we educating the public and more specifically mental healthcare providers about this bridge between supposedly mandatory Duty to Warn Provisions that are actually permissive and State law requirements that might be mandatory?

Mr. {Rodriguez.} So one of the issues that I think the drafters of our rule in this area were attempting to tackle because we are talking about, I think you are correct, we are talking about both duties and authorities to warn. In other words, when we are talking about the Tarasoff example, there we are talking about an actual duty to warn or to protect.

Mr. {Braley.} But based on State law. Not based upon the language of HIPAA.

Mr. {Rodriguez.} Correct. HIPAA is really meant to get out of the way of those duties and authorities and to clear a wide enough lane for those duties and authorities to be utilized and implemented by providers and for professional judgment to really be the hallmark of when disclosure occurs.

Mr. {Braley.} Well, one of the first forums we had on this subject one of our witnesses was Pete Early, who wrote this book about his son’s journey through the mental health
system and criminal justice system, and he noted appropriately in here that in 1963, President Kennedy signed a National Mental Health Law that authorized Congress to spend up to $3 billion in the coming decades to construct a national network of community mental health centers, and then notes on the next page that Congress never got around to funding or financing community mental health centers.

So the process of deinstitutionalization moving from State mental health institutions to community-based mental healthcare that was supposed to happen instead became a process where more and more people wound up in the criminal justice system, and we now have law enforcement officers who often are providing frontline mental healthcare. And I think for the families of some of the victims who have experienced firsthand the loss of a loved one because of our inability to bridge this gap, especially when a patient is accompanied to a treatment facility by law enforcement officials who have a duty to protect the public safety and they aren’t provided information about the release of that patient, even though there may be a prior history of threats, how do we get to the point where we are protecting the patient’s privacy and at
the same time making sure that we aren’t blocking the
disclosure of information that can protect the public?

Mr. {Rodriguez.} I certainly think we need to continue
our educational efforts, and, again, that is why that
initiative, which, incidentally, was widely covered in
professional media So I think the reminder we sent in
January was something that was really embraced by the mental
health profession is to remind them that at least HIPAA, I
can’t account for all the professional codes and State laws
that also apply here, but at least HIPAA in those kinds of
situations where a danger is posed does not stand as an
obstacle to providers acting in the interest of the patient
and of public safety.

I think it is also worth noting, you know, that there is
a countervailing concern that patients who fear that their
information will not be confidential won’t get treated, and I
think that is why, Congressman, when you talked about that
delicate and difficult balance, that is the balance that both
our regulations and healthcare providers I believe are trying
to strike.

Mr. {Braley.} Mr. Rothstein, one of the other concerns
that Mr. Early raises is that if we have a child in a divorce proceeding or a custody proceeding, the number one role of the court system is to decide what is in the best interest of the child. That is their principle focus. And yet when we have adult patients who are getting mental health treatment who may or may not be able to make decisions about their own treatment needs, oftentimes the legal criteria are not what is in the best instance of the patient but protecting the patient’s wishes from a legal standpoint and that often the advocates focus on that rather than getting the best treatment option that would benefit them in society.

What are the obstacles we need to face to deal with that problem?

Mr. {Rothstein.} It is a very difficult question. The immediate test would be whether the individual is competent, and if the individual was competent, healthcare providers tend to overlook all the other tests. If the individual is competent and a threat to self or others, then that overrules the competency issue. If the individual is incompetent, unable to make reasoned decisions about his or her mental health, then the confidentiality protections would not apply.
Mr. {Braley.} Thank you.

Mr. {Murphy.} The gentleman’s time has expired.

I now recognize the gentlewoman from North Carolina, Ms. Ellmers, for 5 minutes.

Mrs. {Ellmers.} Thank you, Mr. Chairman, and thank you for, again, holding this very, very important mental health hearing, especially in lieu of the forum that we had a couple of weeks ago with the family members, and you know, that was a very important, emotional, and revealing discussion that we had, which brings me to some of the questions that I have because I have practiced in healthcare. I am a nurse. My husband is a general surgeon, and you know, HIPAA can sometimes get in the way, and as healthcare professionals I would say that you would typically err on the side of, you know, protecting the patient’s confidentiality and yourself as a healthcare professional.

Mr. Rodriguez, I would like to ask you since the implementation in 2003, according to my information HHS has received over 79,920 HIPAA complaints. What is the procedure when a complaint comes in?

Mr. {Rodriguez.} Sure. The first thing we do is assess
whether, in fact, it is a HIPAA complaint at all or whether
the complaint is about some other issue outside of our
jurisdiction. If we determine that we do have jurisdiction,
we then conduct an inquiry.

Mrs. {Ellmers.} Uh-huh.

Mr. {Rodriguez.} Conduct an investigation into the
allegations. If we determine that there were violations of
relevant HIPAA requirements, we then work with the entity.
Ordinarily. I am going to talk about the exception in terms
of our Monetary Enforcement Program. Work with the entity to
correct whatever the deficiencies are in their practice in
order for them to go forward and be compliant--

Mrs. {Ellmers.} Uh-huh.

Mr. {Rodriguez.} --in those areas. Now, through High
Tech as you know, we received enhanced monetary enforcement
authorities, particularly directed at concerns about the
security of electronic health information.

Mrs. {Ellmers.} Uh-huh.

Mr. {Rodriguez.} And so since High Tech was passed, our
enforcement specifically focused on security rather than use
and disclosure issues that we have been talking about here,
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41 has, in fact, grown, and in fact, it is been a priority of
mine to grow our enforcement to protect the confidentiality
of electronically--

Mrs. {Ellmers.} Uh-huh.

Mr. {Rodriguez.} --maintained information.

Mrs. {Ellmers.} Yeah. Very important. Mr. Rothstein,
can you tell me, there again, since implementation of HIPAA,
it brings me to the next question of have there been
significant law suits filed? Is that something that you
would have information about with alleged HIPAA violations?
And when I say lawsuits, I mean against healthcare
professionals.

Mr. {Rothstein.} Right. Well, HIPAA does not provide
for a private cause of action.

Mrs. {Ellmers.} Okay.

Mr. {Rothstein.} There have been a few lawsuits
alleging invasion of privacy or some other--

Mrs. {Ellmers.} Okay. So it would have to be--

Mr. {Rothstein.} But they refer to HIPAA violations but
HIPAA doesn’t provide for those.

Mrs. {Ellmers.} Okay, and there, again, I get back to
the issue of healthcare providers who would err on the side of, you know, less information is probably better, just, again, always looking out for the patient and, unfortunately, always having to cover your own self. And that is one of my areas of concern with HIPAA because I do believe it is kind of a gray area and is left up to too much interpretation.

So, Mr. Rodriguez, my final question here, I have a little over a minute, do you have a sense of how often hospitals and staff, you know, actually go over the HIPAA regulations and make sure that they are up to date? Is that done on an annual basis? You know...

Mr. {Rodriguez.} It is, Congresswoman, a variable. We actually did an audit program last year which is when another program required under High Technology, and this was a pilot, and we found a wide range. We found some institutions that take those obligations seriously, do them on a regular, annual basis, ensure that new employees are trained, but there are also many providers where that is not the case. The compliance is all over the board.

Mrs. {Ellmers.} Uh-huh. There, again, unfortunately, so many things fall on this information. I think this is
definitely one of those areas. So thank you very much, and I yield back the remainder of my time.

Mr. {Murphy.} I now recognize Mr. Butterfield for 5 minutes.

Mr. {Butterfield.} Thank you, Mr. Chairman. Let me begin by thanking both of you for your testimony today. I thank you very much. It is obvious that you all are both well prepared.

I will address this question to Mr. Rodriguez. Mr. Rodriguez, following the Newtown tragedy President Obama took appropriate action by clarifying to healthcare providers in writing their duty to warn law enforcement authorities of threats of violence.

First of all, is that true?

Mr. {Rodriguez.} That is true. I signed the letter, but it was at the President’s direction.

Mr. {Butterfield.} Okay. That was going to lead me to my question was it a letter or an executive order, or what was it? It was a letter from your office.

Mr. {Rodriguez.} The letter was really a reminder of existing duties under the law and also of the
Administration’s emphasis that these authorities to warn and these duties to warn should be fully exercised to protect the public safety.

Mr. {Butterfield.} And has that action had any impact as far as you can determine?

Mr. {Rodriguez.} It is had impact in the sense that there has been renewed discussion about these issues. There was extensive industry media coverage of the letter, and so, therefore, we believe based on that that the reminder reached the folks it needed to read, which are those, particularly those mental health providers.

Mr. {Butterfield.} And about how many letters actually went out from your office?

Mr. {Rodriguez.} They were posted on our website and then disseminated by both press release and through various listers that HHS has.

Mr. {Butterfield.} Can you described, Mr. Rodriguez, additional ways the Health Information Technology, HIT, for Economic and Clinical Health Act, which we passed in the Recovery Act, how it has improved privacy and security requirements for patient records?
First of all, it has done so by bringing business associates within the ambit of the privacy and security worlds. That is those contractors who serve healthcare providers, and in fact, often come into possession of large quantities of protected health information. We now directly regulate them as we directed healthcare providers before that. It increases the penalties for violation of HIPAA which we have used extensively for security violations, and it also establishes requirements that breaches of health information need to be reported to our office to the affected patients and in cases of larger breaches, also be reported to relevant media that will be seen by the affected patients.

Mr. {Butterfield.} All right. My third question follows. Can you describe the training that medical professionals receive to ensure they adhere to HIPAA?

Mr. {Rodriguez.} Sure. To my knowledge, I wouldn’t consider this a comprehensive answer, certainly training on HIPAA is offered at many professional conferences. In fact, we actually have prepared a series of videos to be posted, that have been posted, and several more that will be posted
on Medscape, including some that are, by the way, relevant to
the topic we are discussing here, that discuss various
aspects of the privacy and security rules.
We are particularly concerned about smaller providers
who don't necessarily have the resources of larger
institutions. So we are looking for opportunities to reach
them.
I also understand that there are medical school
curricula that touch on these issues as well.

Mr. {Butterfield.} It is my understanding that
healthcare providers covered by HIPAA must notify patients if
the privacy of their health information is breached. What
methods are used to notify those individuals?

Mr. {Rodriguez.} They can be notified, they should
ordinarily be notified in writing, and, again, we also in
certain cases provide for notification through the media.

Mr. {Butterfield.} All right. Finally, Mr. Rothstein,
Dr. Rothstein, even with HIPAA protections we have heard that
privacy concerns can cause individuals to actually avoid
treatment. I am not sure I knew that.

Could increasing information sharing through HIPAA cause
fewer individuals to seek treatment?

Mr. {Rothstein.} That certainly is a concern, especially individuals who have sensitive information that they are worried will be disclosed. Yes.

Mr. {Butterfield.} All right. Mr. Chairman, I yield back.

Mr. {Murphy.} I thank the gentleman.

Dr. Cassidy is not a member of the Oversight and Investigation Committee but has asked an opportunity to join us and without objection we will allow him 5 minutes to ask questions. Dr. Cassidy.

Dr. {Cassidy.} Thank you, Mr.--Chairman Murphy.

Gentlemen, I am a practicing physician, will see patients this Tuesday morning, and I have a sense that you two are incredibly bright and well-versed in this law and is totally divorced from the reality of an ER physician seeing 20 patients in a shift, and at 3:00 a.m. there is a person who comes in with these issues.

I will just tell you, and I will also tell you that physicians fear the Federal Government. They understand that if the Federal Government comes after them and grabs them in
their long legal arm, the physician may ultimately win, but she is destroyed in the process.

         Now, I listened to what you say how this would allow certain forms of communication, but I will also say when I read that the maximum penalty is 1.5 million, when the physician is having their in-service on HIPAA, that is what they remember, and when they understand that it is permissible not to give information, but you may get in trouble if you do, I can tell you that guy, that gal seeing the patient at 3:00 a.m. with 20 patients doesn’t have your expertise, but what they do have are examples of physicians who had been grabbed by the law and not let loose until every one of their personal resources had been exhausted.

         Now, that is just a comment borne out of incredible frustration with this sense that the Federal Government is this benign entity that the American people have no reason to fear. Indeed, it has great reason to fear, and so people act cautiously.

Now, that said, after my rant, I apologize, let me ask a couple things. We say that the doc may communicate with the family if there is imminent danger, but what if the patient
is non-compliant? Can the family say to the mother of the adult child who lives with her, your son is not taking his medicines, and therefore, we need to do something about that? Can the physician do that?

Mr. {Rodriguez.} So, again, we go back to the idea of serious risk to health or safety. So we are not talking about imminent danger in the sense of somebody going out, and it certainly includes that scenario, but it is much broader than that. So if the patient’s health would be seriously, adversely affected and the provider’s communication of that information to the parent would provide a way of eliminating or at least reducing that threat, then HIPAA provides them clear authority.

Dr. {Cassidy.} So the specific example, the patient is bipolar, and I am a little rusty on my psyche so this medicine may no longer be used, but assume that they are on Lithium, and their Lithium level shows that it is low, the patient is not taking their drug. We have documented fact. Can the doc say to the mom, your son is not taking his Lithium?

Mr. {Rodriguez.} You also might have heard the
beginning of my testimony. We were also talking in cases of incapacity.

Dr. {Cassidy.} Of what? I am sorry.

Mr. {Rodriguez.} Of incapacity.

Dr. {Cassidy.} No. I am not saying they are incapacitated because when that level falls, they don’t immediately become incapacitated. They are just on the potential verge of being but they can still seem sane.

Mr. {Rodriguez.} Well, then I think the pathway is—if the result of that would be a serious consequences for that individual’s health, then HIPAA provides a path for those communications.

Dr. {Cassidy.} There seems to be a little bit of wiggle room there. The guy could get back on his dose and bring it back up to snuff. I am not sure the physician would find a safe harbor in that kind of answer.

Mr. {Rodriguez.} Well, I think the greater safe harbor, Congressman, would be this. We have received 80,000 cases since we began enforcing. Only 12 of them have resulted in monetary penalties.

Dr. {Cassidy.} I accept that, but what you are talking
about is a fellow seeing patients 20 in a shift at 3:00 a.m. in the morning who doesn’t have your expertise. That is the reality, and I can tell you that what you hear in that in-service is that if you violate HIPAA, they are going to turn you every which way but loose. I can tell you that is what the in-service is because I have been there.

Mr. {Rodriguez.} I would love to see those in-services because they are not consistent with our enforcement history.

Dr. {Cassidy.} Secondly, it says here that the patient healthcare provider is not permitted to share personal information with the family or friends of an adult who tells the provider not to do so. What if that patient is incompetent? What if they actually at this point in time are not lucid? They think that there is black helicopters circulating and that their mom is the pilot of one of them.

Mr. {Rodriguez.} And that is why I mentioned—that is certainly in cases of incapacity and certainly incapacity can include a situation where a patient is far from lucid, then in those cases there is also a basis for--

Dr. {Cassidy.} Now, sometimes lack of lucidity is in the eye of the beholder. I will tell you that there is a
Wall Street Journal article about William Brice or Bruce, I forget which, in which the young man was released and went out and killed his mother with a hatchet. And so clearly he was considered lucid enough to be released.

I am sorry. I am out of time. I apologize. I will have to forego. I yield back. I am sorry.

Mr. {Murphy.} The Chair is going to ask that everybody be permitted 1 minute of additional questions, and then we will get onto our next panel, recognizing we have votes recognizing we have votes coming up soon. So we will do 1 minute.

Mr. Rodriguez, as you are aware, States have said, confusion over HIPAA has prohibited them from sharing 1.5 million records with the National Instant Background Check System of persons who have been involuntary committed to mental health treatment or deemed mentally incompetent by a court of law and are, therefore, prohibited from owning a firearm. Our committee sent a letter to HHS on February 13 asking about HIPAA interfering with this NICS list. I note that HHS has now announced it would be soliciting feedback on HIPAA reform.
Why do you believe States are not uploading those records?

Mr. {Rodriguez.} I certainly have heard of HIPAA as one of several different reasons, so I don’t understand HIPAA to be the only reason. I know certainly in the case of New York State they are reporting was coming out of or their reporting would have had to have come out of what was a HIPAA-covered entity and therefore, reporting would have been prohibited, and we are now looking to eliminate that kind of barrier. Beyond New York I don’t know if there are others.

Mr. {Murphy.} Can you get us a written response to the subcommittee on this issue clarifying it?

Mr. {Rodriguez.} Sure.

Mr. {Murphy.} Thank you. Mr. Braley, 1 minute.

Mr. {Braley.} Mr. Rothstein, we were talking earlier about some of the challenges faced with the incredible burdens placed on law enforcement officials, our penal systems to provide front-line mental healthcare. This has been a dramatic shift in what has happened since Congress passed legislation trying to promote community-based mental health.
So we now have this long learning experience, and people who care about the rights of the mentally ill, like I do, people who care about protecting public safety, like I do, want to know what we have learned from these experiences as we move forward and try to create a balanced system that is protecting the public and the rights of patients to get the best possible treatment when obviously we have been failing them. What can we do about that?

Mr. {Rothstein.} Well, Mr. Braley, that is a difficult question. On the one hand we need to increase the funding and wherewithal of community mental health services. That is for sure. What we can address at this hearing today is the importance of getting out the message of what HIPAA does and does not require.

One of the problems overall is that HIPAA was intended to be a floor above which medical ethics and State law would take place, but in many areas, including mental health areas, it is the floor, and there is nothing else above it.

Mr. {Murphy.} You can offer a written response, too, we would appreciate that, because we are going to need more detail.
Dr. Gingrey, you are recognized for 1 minute.

Dr. {Gingrey.} Mr. Chairman, thank you. I don’t know if I can do this in a minute but quickly.

Mr. Rodriguez, on January 25, 2013, HHS published a final rule that makes, and I quote, ”significant modifications to marketing by third parties to patients for purposes of identifying potential beneficial health opportunities for patients.” For instance, many drug companies use third parties to help identify patients in need of care for purposes of inclusion in clinical trials. Some of these patients, including those from my own district, have chronic illnesses for which no other treatment option exists. Would this service still be allowed if such a company, third-party company, did not first get the patient’s consent?

Mr. {Rodriguez.} It is a long answer, so I will take advantage of the opportunity to offer it in writing.

Dr. {Gingrey.} All right. Thank you, and I yield back.

Mr. {Murphy.} Dr. Cassidy, 1 minute.

Dr. {Cassidy.} Mr. Rothstein, I am little concerned.

You mentioned the point there is 26 percent of the people who have a diagnosed mental disorder in 1 year, but really if you
talk about serious mental illness it is really a much smaller percentage.

Mr. {Rothstein.} Of course.

Dr. {Cassidy.} And those are the folks who are incompetent that, I mean, believe me, I speak from personal experience of family members and of friends who have been in this situation. Don’t you think it is a little disingenuous to say, okay, here is a group that truly are out of it as opposed to this 26 percent that have situational depression or such like this.

Wouldn’t it be more honest to kind of focus upon that SMI group for their sake, their family’s sake as a unique group?

Mr. {Rothstein.} Oh, absolutely, but the point I was trying to make was if legislation were enacted that made all mental health records more discloseable--

Dr. {Cassidy.} So you would accept maybe SMI under very guarded circumstances--

Mr. {Rothstein.} Of course.

Dr. {Cassidy.} --as opposed to the broader 26 percent of the population?
Mr. {Rothstein.} That is correct, but I am worried about the discouragement of the 26 percent.

Dr. {Cassidy.} I would just say, someone who has got bipolar or schizoaffective oftentimes does not have that insight, and I think we have to be kind of honest about that. They have an acute break, and they have no insight whatsoever. As a guy who has worked with such patients and who has had close people associated.

I yield back. Thank you.

Mr. {Murphy.} Thank you. Mr. Rodriguez, Mr. Rothstein, thank you so much for being with us today, and we appreciate your availability in the future to respond to questions.

As they are stepping up, we ask the folks to get ready for the second panel. I would like to make an announcement.

As we continue on with our previous hearing after Newtown and also this one on HIPAA, this committee is exploring the issues of a wide range that deal with mental illness and proper treatment, et cetera, because of our concerns.

I want to make it very clear, all members are aware of this, but certainly members of the audience and people who
may be watching this also, at no time does this committee at any time communicate that those with mental illness are those who are responsible for violence. We recognize that victims, that they are actually 11 times more likely to be victims of violent crime than non-mentally ill, and the vast majority of people with mental illness are not violent. It is very important we understand that.

Could the next panel please take their seats, and we will move forward then?

As you sit down I will be introducing you. On the second panel we have Dr. Richard Martini. He is a Professor of Pediatrics and Psychiatry at the University of Utah School of Medicine and the Chair of the Department of Psychiatry and Behavioral Health at the Primary Children’s Medical Center in Utah. For full disclosure I want to say when I was on the staff at Children’s Hospital in Pittsburgh he was one of my students. How time flies.

We also have Ms. Carol Levine. She directs the United Hospital Fund Families and Health Care Project, which focuses on developing partnerships between healthcare professionals and family caregivers, especially during transition in
healthcare settings.

Next we have Mr. Gregg Wolfe. Mr. Wolfe is the father of a son who suffered from mental illness and substance addiction.

Then we have Mr. Edward Kelley. Mr. Kelley is also a father of a son with mental illness.

And Mr. Braley, would you like to also recognize your guest today?

Mr. {Braley.} Yes. Thank you, Mr. Chairman. I am thrilled to have one of my constituents testify today, Jan Thomas, from Parkersburg, Iowa. She has a story to tell about this gentleman who was featured in Sports Illustrated after he was gunned down by a former student. He was the NFL national high school coach of the year with four of his former players playing in the National Football League, and Jan has an important story to share with us about these issues.

Mr. {Murphy.} Thank you and finally we have Ms. Deven McGraw. Ms. McGraw is the Director of the Health Privacy Project at the Center for Democracy and Technology.

As you all are aware, the committee is holding an
investigative hearing, and when doing so, has a practice of taking testimony under oath. Do any of you have any objections to testifying under oath?

The Chair then advises that under the rules of the House and the rules of the committee you are entitled to be advised by counsel. Do you desire to be advised by counsel during your testimony today?

All answer negatively. In that case would you all please rise and raise your right hand, and I will swear you in.

[Witnesses sworn]

Mr. {Murphy.} The Chair recognizes all of the participants answered in the affirmative. You are now under oath and subject to the penalties set forth in Title XVIII, Section 1001 of the United States Code. You may each now give a 5-minute summary of your written testimony.

We now recognize Dr. Martini for 5 minutes. Make sure your microphone is on and pulled close. Thank you.
Dr. (Martini.)  Good morning, Chairman Murphy, members of the subcommittee. I also want to say I am also an immediate past Board Member of the American Academy of Child and Adolescent Psychiatry, who paid for my travel here today. Thank you for inviting me to come and to speak with you about HIPAA and its implications of clinical practice and to participate in this discussion. Throughout my testimony I
will be reviewing patient summaries that are based upon my clinical experience but that do not include easily-identifiable information.

Decisions about the release of psychiatric information are certainly more straightforward when the patient is a minor and not emancipated. Parents or primary caregivers are involved in the process, are available not only to support the patient, but also to guide them into psychiatric care. Young patients do not typically recognize the nature or extent of their behavioral and emotional problems, and this is one reason why child and adolescent psychiatrists, as well as other pediatric mental health professionals, are trained to involve families in diagnosis and treatment. We also know that this improves outcome.

All pediatric specialties struggle with the transition of their patients from adolescence into young adulthood, from a period of dependence to a period of almost complete autonomy. Many are not prepared for the responsibility, particularly those patients that experience chronic medical illnesses, developmental delays, and psychiatric disorders. Families have provided a framework for their care and for
One of my patients, a former patient with a mild form of autism, developmental delay, and an anxiety disorder was determined to move out of the home once he was employed. The parents knew, however, that he could not manage his money, that he was emotionally reactive when faced with new experiences, and he really could not track his medications. Nevertheless, he did not want his parents involved in routine care. It forced the parents to go to court, state that their son was not able to care for himself, and must be dependent. Unfortunately, the subsequent ruling in their favor was counter to our goals in psychiatric treatment, and it derailed his progress in therapy.

Psychiatrists spend a lot of time negotiating communications between parents and their children, and we don't want to discourage anyone from accessing care, specifically those who will not seek treatment if they believe that someone will contact or involve their parents. However, the application of HIPAA regulations should be a negotiation with several options available to both the clinician and the patient. A patient of mine in his early
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20’s suffered from a long history of congenital kidney disease. He was in and out of the hospital, usually in the company of his mother. He came into treatment because he was angry and depressed over the circumstances of his disease and his subsequent organ transplantation. I wanted to involve the mother in therapy as a support, but he refused because he was concerned about how disappointed she would be given everything that they had gone through together. He was in treatment for about a year, and he was on antidepressant medications but dropped out of treatment because it was too difficult. Two years later I ran into his physician who told me that he discontinued his kidney medications, went into renal failure, and died.

Psychiatrists should be able to both respect the individuality of the adolescent or young adult under the legal protection of HIPAA and use the strengths of the family when necessary to support treatment. I recognize that allowing more communication and less privacy for an adult patient at risk for a serious mental illness is a significant change in the intent of the law, but must we wait for a patient to be considered at risk for imminent harm to self or
others before seeking help from parents or family?

Rules about confidentiality certainly affect situations that are relatively more common among adolescence and young adults, like going to college. Parents are told that even though they are going be paying the bills, they will not have access to any medical or psychiatric information without the student’s permission. One such patient with a history of congenital heart disease and ongoing depression wanted to go away to college. Her parents wanted her to stay close to home. She prevailed, but within 3 months of going to school, she began to deteriorate both medically and psychiatrically. The Student Health Center knew that she was ill but without her permission could not contact the parents. If this patient had a really serious disorder with immediate consequences, the family may not find out about it until they receive a bill some 30 days after the event. If there is a bias in these situations, should it be toward parental involvement more than away from it?

Mental health professionals strive to do what is in the best interest of the patient, while preserving his or her right to privacy and protection under the law. The basis for
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civil commitment and family communication regardless of the patient’s wishes has been risk of harm to self or others. I suggest that this standard be reexamined with the goal of involving families whenever possible.

Thank you, Mr. Chairman.

[The prepared statement of Dr. Martini follows:]

*************** INSERT 3 ***************
Mr. {Murphy.} Thank you, and Ms. Levine, you are recognized for 5 minutes.
Ms. Levine. Chairman Murphy, members of the committee, thank you very much for inviting me here today. I am at the other end of the age spectrum. I work with family caregivers of older adults who are with multiple chronic illnesses, and I think the importance of my experience for your deliberations is that the misinterpretations of HIPAA which we have heard about from Mr. Rodriguez and Mr. Rothstein are far more pervasive than the specific questions of mental illness.

There are about 42 million Americans who are taking care of their chronically-ill older parents or other relatives, and I can’t tell you how many times I hear from family caregivers who have a parent in the hospital, and the family member is expected to do a wound care, multiple medications, monitor machines, and all sorts of--make all the care coordination in the community, and when you ask about what do I need to know to do this, they say, well, I can’t tell you because of HIPAA. And that is just simply wrong and why does
It happen? Because of the two features that have already been mentioned.

There is this training that emphasizes the scary aspects of HIPAA. It is often done in a way that if you say anything, you are going to be in big trouble. That—and if the training doesn’t say that, then the informal communication among healthcare providers, particularly from the mid-level staff, it is not necessarily physicians but nurses, social workers, others, terrified that they are going to get sued, they are going to lose their job. Meanwhile, laptops lie all over the place. They are not paying attention to the actual security of this information.

The second reason, and I think this is very pervasive, also alluded to, HIPAA has become a very convenient excuse to avoid difficult conversations with families. It takes time, it is sometimes uncomfortable, it has really nothing to do with privacy of the patient’s information. It has to do with I don’t—why am I—why do I have to talk to this daughter? Why can’t I just tell the patient? Well, fine, if the patient is totally able to understand, but an 85-year-old woman with congestive heart failure, moderate dementia, 55
other medications and so forth, just cannot absorb that information.

So I think that what we really need is far more education on a balanced level. I think it is instructive that our next, United Hospital Fund’s Next Step in Care website, guides for family care, the most downloaded guide is the one to HIPAA. So people are confused, and they are looking for information. And I think that hospitals, the covered entities, wherever they are, need to be encouraged to provide understandable information to their patients, to the families, to everyone they deal with. You go to a hospital now, you get a piece of paper to sign or several pieces of paper. You can barely understand. I think only Mr. Rothstein and Mr. Rodriguez and several members of the committee here would actually be able to understand it, and mostly it is about what we could do with more information. It is not about protecting the patient’s interests at all. I think my ultimate question is always whose interests are being protected? Is it the patient’s interests? Is it the staff members’ interests in not getting into trouble? I appreciate that. Or is it the institution’s interests in not
making any kind of--not being, also not being in trouble, and
those are valid, but they should never override the good
clinical care, the importance of good communication that
older people, younger people, everyone needs to get the best
possible clinical care. So it is a very pervasive problem.
It goes beyond what you are specifically asking about, but I
think in all it is a kind of waterfall. Once it starts, it
keeps going, and we continue to hope for more clarification.
Thank you.
[The prepared statement of Ms. Levine follows:]
Mr. {Murphy.} Thank you, and Mr. Wolfe, you are recognized for 5 minutes.
Mr. Wolfe. Good morning, Chairman Murphy and members of the Oversight Committee. My name is Gregg Wolfe, CEO of Kaplan, Leaman, and Wolfe Court Reporting and Litigation Support and Federal Official Court Reporter for the Eastern District of Pennsylvania.

I am very thankful for the invitation extended to me so that I may testify to address the necessary and dire need to change the HIPAA law regarding minors and legally emancipated adults who either have a mental disorder, disability, or drug and/or alcohol addiction. I will set forth the reasoning for the exception to our valuable HIPAA law, which will have a positive impact on our society.

My son, Justin, was a gregarious, affectionate, caring, compassionate, and intelligent young man whose life came to a sudden end on December 19, 2012, from a heroin overdose at the very young age of 21.

Justin had attended Drexel and Syracuse Universities for his freshman and sophomore years respectively, carried a 3.0
GPA, but each year ended poorly due to aberrant behavior. Justin had been seeing therapists since he was 15-1/2 due to anxiety, OCD, and ADHD.

He was placed on Adderall when he was almost 17 years old. Unlike physical illness, mental illness has a much longer maturation and duration until one discovers the effects and results with which to treat and possibly cure.

In 2012, Justin told his mother that he was addicted to Percocets and Oxycontin. She, in turn, took him to our primary care physician without my knowledge, per Justin’s request. At that time, Justin apprised the doctor of his addiction, but also, when his mother was not present in the room, he stated that he had been using heroin for a few months prior to that date.

Justin had asked that I not be apprised of any of those substances and did not want his mother being informed of his heroin usage. Without disclosing the heroin usage, the doctor expressed dire concern to Justin’s mother and told her to take him immediately to a recommended crisis center for treatment. However, upon departing the office, Justin convinced his mother, through his drug-manipulative behavior,
to take him instead to a Suboxone doctor he knew of, which she did.

Justin would not allow his mother into the treatment room. There Justin admitted to using heroin for the previous year, and he was prescribed Suboxone.

Two months later, against Justin’s wishes, I was only informed of his Percocet addiction and implored him to enter into drug rehabilitation treatment. Justin was working two jobs during this time, with little time to attend treatment. Additionally, he convinced his mother and I the Suboxone was helping him with his recovery.

As another month passed, Justin was residing in his college apartment, and he finally hit rock bottom. We finally took him--we finally gave him an ultimatum, and he entered intensive outpatient treatment for 5 weeks that summer. Once in rehab, I contacted the intake director to inquire about his progress. I was informed that he could not disclose any information under the HIPAA regulations. I was extremely frustrated as I could not be apprised of my son’s condition.

During Justin’s 5-week rehabilitation, I sent him to see
an experienced psychiatrist weekly, which ensued until his ultimate demise this past December. I explained to the psychiatrist his history with abuse, for which he tried to counsel Justin, as well as to prescribe medication for his depression, anxiety, and OCD. I later learned, however, upon Justin’s passing, that he had not disclosed his heroin addiction to the psychiatrist, except to say that he had tried it once.

Upon Justin’s passing, his depression and OCD medication were found untouched in his apartment. Oddly, he continued to take his anxiety medication. Justin returned to school last fall at Temple University where he appeared to be doing well. He even joined AEPI, a wonderful fraternity, where he pledged and was fully supported by the brotherhood.

However, Justin obviously was terribly and secretly addicted to heroin, in addition to having mental disorders. He died of an accidental overdose, heroin overdose just a few weeks later.

Though doctors knew since May, 2011, no one in our family was aware that Justin was using heroin, a lethal and insidious drug. Everyone was in shock and disbelief when we
found out. Nevertheless, it was too late.

I have confronted numerous parents, and nine out of ten people are not aware that snorting heroin is an option, which is how Justin used the drug, not by injection. Most are also shocked to learn that heroin is only $5 to $10 a bag.

It was alarming to learn that it is actually cheaper to buy a bag of heroin on the street than it is to purchase Percocet and Oxycontin. Even kids from affluent suburban neighborhoods like my son traveled to dangerous places like Camden, NJ, and North Philadelphia in Pennsylvania to buy drugs. Justin sold some of his personal belongings and items stolen from his mother, pawned his computer on several occasions, and actually sold his Suboxone and Adderall medication, which I learned after the fact by reading his text messages.

I hereby request an exception be added to HIPAA allowing parents of minors with a mental disorder or addiction, who maintain legal residency in their parents’ homes, living under the auspices of their parents’ care, and who are under their parents’ health insurance coverage as specified by President Obama, until the age of 26, access to that minor’s
medical records for the following reason: prevention of harm to individuals and to society.

One. Any type of addiction or mental disorder can be life threatening to not only one’s self but to society as a whole as indicative of the Newtown Massacres, Columbine, the Aurora shootings, to name just a few.

Justin was non-violent and would never intentionally hurt a soul, but unintentionally his life cut short destroyed other lives including his younger brother, Austin, who is a Type 1 diabetic, not to mention the individuals to whom he sold his Suboxone and Adderall. After Justin’s passing, Austin told us of his reckless disregard when driving as well as when conducting some of his activities. Thank God he never hurt anyone on the road. I have pictures of Justin’s apartment from his last months that demonstrate how he resided at college, including cigarette burns in his bedding from obviously nodding out, which could have set the apartment complex ablaze, resulting in injury or death to himself and others.

Two. Justin’s stepfather had taken him assault rifle target shooting on occasion for sport. Had we known about...
his heroin addiction, he would not have armed him. Justin
had often asked my permission to become licensed to buy a
gun, which I was against despite not knowing about his
addiction. However, I am forever thankful for not allowing
it, especially now that I know he was using a mind-bending
drug.

Mr. {Murphy.} Mr. Wolfe, I know—we are out of time. Can you give a final summary, and we can have you come back
to that element two? Is there a final summary you can give
to your statement there?

Mr. {Wolfe.} I do. I have some very important points
to make, and it will only take 3 or 4 more minutes.

Mr. {Murphy.} I will give you an additional minute. Go
ahead.

Mr. {Wolfe.} Thank you.

Three. Justin’s lying and manipulation was the result
of his heroin addiction. I have learned that heroin rewiresthe synapses of the brain so the only way to experience
pleasure is by doing more of the drug. One becomes numb to
all other surroundings, emotions, and empathy, thereby
resulting in the aforementioned behavior.
Drug-related deaths have risen steadily over the last 11 years according to a study from the Center for Disease Control. In 2010, drug overdoses killed 38,000 people, making drugs a more common cause of death than car accidents, guns, or alcohol. By comparison, approximately 8,500 homicides were the result of firearms.

According to a 2011, article in Psychology Today, accidental drug overdosing is the second most cause of death of young people in the U.S., exceeding attributable to firearms, homicides, or HIV AIDS.

According to the U.S. Department of Health and Human Services, "With an immature prefrontal cortex, which does not develop until 24 to 25 years old, even if teens understand that something is dangerous, they may still go ahead and engage in risky behavior." With young adults not having their frontage cortex fully developed, those with mental disorders and or addictions exacerbate the irrational behavior.

In many circumstances, parents know what is best for their children, especially if given the appropriate medical information with which to exercise judgment and guidance. In
an effort to help other parents in similar situations, I have launched an all-out campaign to the media, President Obama, lawmakers in New Jersey, Pennsylvania, and Delaware, and Congressional leaders such as yourselves to call attention to this issue, and to lobby for adding language to HIPAA that may help protect troubled young adults and their communities from harm.

Parents are unable to operate effectively in a vacuum, without knowledge by healthcare professionals about our drug-induced, or mentally disabled, legally-aged children who do not have the wherewithal to reason or think rationally for themselves. The absence of rationale may result in life-threatening decisions or, as in my son’s case, premature death.

HIPAA has exceptions for public health and safety built-in. Item number five under Permitted Uses and Disclosures whereby protected health information can be disclosed without an individual’s consent, including, Serious threat to Health or Safety. Covered entities may disclose protected health information that they believe is necessary to prevent or lessen a serious and imminent threat to a person or the
public, when such disclosure is made to someone they believe can prevent or lessen the threat, including the target of the threat.'' So it should stand to reason language addressing this particular safety hazard is prudent and necessary.

In closing, I am hereby requesting the following language be added to this HIPAA exception to avoid ambiguity.

Parents or legal caretakers of a minor and/or emancipated adult with documented drug abuse and/or mental health histories, who continue to cover the minor and/or emancipated adult with health coverage, and/or continue to support the individual financially, will have access to that individual’s healthcare records until the age of 26 to prevent him/her or society from harm.

Although Justin’s family, friends, nor Justin himself, could not save him, it is my hope that with change Justin’s situation can help save millions of young lives in the future. Addiction and mental disabilities wreak havoc on our society and affect all ethnicities and socioeconomic backgrounds.

When you look at all the famous and intelligent people whose lives were tragically taken due to mental disturbances
and drug abuse, this country has lost a wealth of talent and
success which would have been an asset to the growth and
strength of our Nation.

Thank you very much.

[The prepared statement of Mr. Wolfe follows:]

*************** INSERT 5 ******************
Mr. {Murphy.} Thank you. Mr. Kelley, you are recognized for 5 minutes. Mr. Kelley.
Mr. {Kelley.} Thank you, Mr. Chairman. I am a father of a paranoid schizophrenic son. He was diagnosed at age 14, which means for half his life he has had this illness, and I am afraid I have some rather harsh news and some points to make that are going to fall in line, and I thank Congressman Cassidy for his comments because he really gets right to the point.

My wife and I, upon learning of this diagnosis, embarked upon educating ourselves in every aspect of mental health treatment, including navigating the system, familiarizing ourselves with all the things that are in our way, and then we took upon ourselves to go out and educate others, and we have done that by teaching classes, we have done that by serving on boards, we have done that by speaking engagements, we have done it by raising money, and we have also done it by bringing people into our home and comforting them and helping them to cope.

And so what I am going to tell you is that we are
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actually ashamed of ourselves as to what we did not know before our son became mentally ill, and I would dare say that if the members of this committee were to spend a couple of days with someone with psychosis, this would fly. You would change things tomorrow.

And so what needs to happen is there needs to be recognition that there is a gaping hole, and I want to clarify something. There is a difference between anosognosia, which is lack of insight, and a psychotic episode. They are two entirely different things.

Anosognosia can last for long, long periods of time and lack of insight, and you refuse treatment, and you don’t want anybody to help you of any kind, most importantly your family members. Not just parents. Brothers, sisters, grandparents.

And so what happens is you are setting a stage for tragedy, literally propping it up because there is this gaping hole we are trying to teach or trying to address the needs of the severely mentally ill the same way we are the mainstream mentally ill population, and it doesn’t work. It is illogical.

My son has thought he has been a U.S. marshal looking
for his gun. He has been—thought the aliens were invading
him. He thought he was a secret agent. He thought—he
thinks to this day he served in two Iraq wars. He has been
naked in the snow. He has lived homeless under a bridge. He
thinks my wife is a stripper and a prostitute and that I am a
sexual predator. For an entire year he did not believe that
we were his parents. Now, you tell me that this individual
can possibly make responsible decisions about his care.

But when he gets into the hospital, and that is a big if
because sometimes we don’t have the recent history from prior
hospitalizations to give the new hospital. By the way, he
has been in 14—for 14 years he has been in eight hospitals
in four counties and one city dozens of different times. And
so you have this broken chain of treatment.

So imagine a medical system where physicians and
treatment providers can’t rely on prior history to treat this
person. It is beyond comprehension, and the other thing that
happens is it stifles accountability, and now, when I tell
you that people hide behind HIPAA, I am a 14-year-educated
man that has been in every situation possible, and it is only
the grace of God and I think there is a plan out there for my
wife and I to somehow make a difference, that we are sitting
here and that our son hasn’t killed himself. He is far more
likely to kill himself than he is to live the rest of his
life with his illness.

And so what we find is that once he gets in the
hospital, treatment can be delayed or not done at all, and I
want to cite this example. Our son escaped from a mental
health facility that was locked. HIPAA was thrown out the
window. The hospital was calling us, the police were calling
us, they were trying to pry into his bank records. Every
privacy violation you can imagine was enacted to try to do
this manhunt for my son. They found him 4 days later. They
dragged him into a state hospital in shackles so we can talk
about stigma later. Once he was in there he verbally
assaulted the Administrative Hearing Judge, he was put on
suicide watch, he was completely out of it, and when the time
came for his hearing to see whether he should receive
treatment, we were precluded from participating because of
HIPAA, and that panel looked me in the eye afterwards and
said, we can’t do it. Our hands are tied.

Two days later a patient was--a staff member was killed
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in his wing. We don’t even want to know what happened, but this is what did happen. He was 1 year, 1 year in that facility. The abuse, the things that happened to him in that hospital and they never, ever let us in. When he was 18, they couldn’t live without us. When he became 18, we were the enemy. We might as well have been strangers on the street. We have doctors who have shared with us behind the scenes some things that they knew they were going to get in trouble with. They told us, we can lose our jobs, but we have to tell you. We are members of community, and people know us, so people took chances, but when we got outside of our community, there were no changes being taken, and we were left out.

The other thing that happens is imagine somebody who is mentally ill being discharged back into real society. Even under the best plans with families being involved, it is a very difficult process. But take a look at someone who is not part of a discharge plan that includes a support network. Our son has been released and sent on buses, and we haven’t found him for weeks, wondering if he is dead.

HIPAA empowers homelessness. Our son has been gone. No
money, no clothes that are adequate, nothing. Gone. We look around in shelters. Gone. We say why didn’t you tell us? We can’t. HIPAA precludes that. And we say, we thought—and then this whole idea, this notion that they have to tell us if it is a threat to us. Well, they are not supposed to let him out if they are a threat. So they have already decided he is not a threat, so they won’t let us do it.

So we search for him, the shelters can’t tell that they are there, and then the next thing that happens is this person who has been released, you don’t want this person released like this. No support, isolated, in fear, frustrated, angry, and we are his first target. Right? We are the first target.

And so people are being released every day without discharge plans involving the family, and they have no way to transition back into life, and you don’t want that. You don’t want somebody that has psychosis as a symptom that pops up, and by the way, this idea of anticipating and predicting when imminent danger is coming, I just fought in the State of Maryland for 4 months to try to get that across. Not one person on this planet can predict the tipping point of
someone with a severe mental illness. You can’t do it.

So what you try to do is you rely on who? You rely on the people closest to that person, and who is that is the family, but the family can’t do it. We can’t give recent history to the next hospital or doctor because we can’t get it, so what is worse is as each year goes by, we have less ability to help. So this idea that we are going to provide information to the hospital, it doesn’t work, and it is scary.

So in closing, I would like to say that HIPAA has a lot of gaping holes in it. This is the biggest, but if there are ways to beat HIPAA, we seek to find it, which is bad. Our son and other people’s sons and parents deserve the right to be collaborative and informed so that they are safe and their child is safe.

Thank you.

[The prepared statement of Mr. Kelley follows:]
Mr. {Murphy.} Thank you, Mr. Kelley. Ms. Thomas, you are recognized for 5 minutes. Thank you.
Ms. {Thomas.} First of all, I would like to thank Congressman Braley for asking me to come to Washington to tell my story, and I would like to thank Chairman Murphy and Representative DeGette for holding this hearing today on this very important subject. My name is Jan Thomas, and the story I have to tell is a nightmare that could have prevented. My life has not been the same since this tragedy occurred, and it changed the lives of my entire family and my community.

On June 24, 2009, what started out as a normal beautiful spring morning ended up being the beginning of a nightmare. Shortly before 8:00 am, a 24-year-old former student, Mark Becker, walked into our high school weight room, and in front of 22 young high school students emptied his gun at close range into my husband, Ed. Ed did not survive his injuries, and he died on the way to the hospital. He was only 58 years old, and he had taught and coached for 36 years.

In one quick moment, so many lives were impacted forever. Our family lost a son, husband, father,
grandfather, and brother whom we all loved very much. The students in the weight room that day, along with our extended community, lost a mentor, friend, teacher, and a coach. They lost their sense of confidence and security, and the horror of that day will be with them forever.

Innocent youngsters, including our own young grandsons, suddenly realized that the world has a dark side. They were taught a horrible but truthful lesson that day. Bad things do happen to good people for no explainable reason, even when they think they are safe.

Our grandsons were robbed of the deep love of their grandpa, and they will miss all of the experiences they could have had with him. My sons lost their father, whom they loved very much, and I lost my husband and my life partner on that day, and we miss him every day.

But the real tragedy of that day is the fact that it could have been prevented. Only 4 days before Ed was murdered, this same young man rammed his car into the garage of an acquaintance and tried to break his way into the home with a baseball bat. When police arrived, he fled in his car, leading the law enforcement on a high-speed chase. When
the police finally apprehended him, he was taken to an area
hospital for psychological evaluation.

Less than 24 hours before my husband died, Mark decided
he didn’t want to stay at the hospital, and so not following
the advice of his doctor, Mark was dismissed.

No one knew. Law enforcement was not notified, even
though they had requested that the hospital let them know
when he was going to be dismissed. The hospital’s
justification for not notifying the law enforcement prior to
his release was that HIPAA prevented this disclosure. Even
his parents did not know until they were called, until Mark
himself called them later that evening.

No one knew that Mark had been released, but Mark’s
privacy had been protected. During the investigation into
the murder, it was revealed to us that Mark had feelings of
animosity and resentment toward Ed. We didn’t know that. If
Mark had come to my home that morning and asked where Ed was,
I would have innocently sent Ed’s killer directly to him and
Ed to his grave, and what a horror to think that I may have
had to live with that.

Once again, Mark’s privacy was protected. Adults with
severe mental illnesses are not always able to make good choices for themselves concerning their treatment or their actions. They may need help of a family member or other responsible parties to be sure they receive required treatment. They may need outsiders to keep them and others out of harm’s way, but due to HIPAA, even Mark’s parents were unable to get requested information or help make decisions for his treatment.

So I would ask you. Is the privacy of one individual more sacred than a life? Is it more important than the welfare of our general public? Is it more important than allowing our law enforcement to know when a potentially dangerous offender is being released back into the very community that they risk their own lives every day to protect?

Ed was an inspiration to so many in our community, and most importantly, he was a loving son, father, grandfather, and brother. I urge Congress to update this law so we can prevent further tragedies like this one.

Thank you.

[The prepared statement of Ms. Thomas follows:]
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Mr. {Murphy.} Thank you, Ms. Thomas. Ms. McGraw will be recognized for 5 minutes.
Ms. {McGraw.} Thank you very much. I really appreciate this opportunity, and I want to thank the Chairman and the subcommittee for focusing on these issues which are clearly very critical. I direct the Health Privacy Project at an organization called the Center for Democracy and Technology, which is a non-profit public interest in advocacy organization that works on behalf of consumers.

We like to think of privacy as playing an incredibly important role in making sure that people who are suffering from stigmatizing conditions like mental illness will actually get into treatment. Many people express, one out of six in surveys consistently, that if they didn’t have some guarantees in confidentiality that they would not seek treatment, and that is the reason why we have privacy laws. They are not aimed at trying to create obstacles for people necessarily but to create the kind of treatment environment that people with stigmatizing conditions with want to be in.

Having said that, they are not absolute. They have lots
of exceptions, and the previous panel talked about them, some
of the members of this panel have talked about them as well,
that allow for the notification of persons in the event of a
serious and imminent threat and also notification of family
members except in cases where there has been an objection by
a patient who has the right to object. So in this case it
would be either an adult or an emancipated minor or in some
States that allow minors to consent for treatment on their
own and to be able to control their privacy rights. In that
case the minor would hold the right. If that objection has
not occurred or you are not dealing with someone who is
incapacitated, HIPAA does provide for the ability for
providers to share information with family members, with
close friends, or with people that the patient designates.
Having said that, I think it is abundantly clear from
the testimony that we have heard today that HIPAA is badly
mangled in terms of how people interpret it, and using it
frequently as a shield not to disclose information or because
they fear liability, which, frankly, is not anywhere in
HIPAA, and it is--what is incredibly frustrating to me when I
hear these stories, and I am sure it is frustrating for all
of you, too, is that, you know, HIPAA doesn’t say you can’t
disclose. So for people to blame this on HIPAA is just
incredibly frustrating because, in fact, HIPAA does allow
those disclosures in those cases, and where the disconnect is
happening is just incredibly frustrating to me. Again, I am
a privacy advocate, but I believe in the reasons for these
exceptions. We try to take a very balanced approach to these
issues and understand the reason why those exceptions exist,
and yet for whatever reason the myth that you can’t disclose
to family members, and, again, this is—the disclosure to
family members are not bound by the potential for a serious
and imminent threat.

It is the case, though, that if an individual objects,
again, if they have the competency and the power to object,
then that would be the case where you couldn’t disclose. But
it is—I would say more often than not there is, you know,
again, experiences of the folks at this table
notwithstanding, people actually want their family involved
in their care. I have had people say to me, I would--my
mother, my elderly mother, who I am caring for, I would like
to be able to have her doctor talk to me about her treatment
and yet that office is telling me that HIPAA will not allow it to happen. And that is so untrue and so I am incredibly sympathetic to the frustration of people who are told that HIPAA requires something that it doesn’t, and I am trying to figure out what we can do better in terms of educating folks about what HIPAA does and what it doesn’t do because it sounds to me like too many people are hiding behind it in circumstances where there are clear exceptions that would allow for that information to be shared.

Some of the testimony of Director Rodriguez in the first panel, there, frankly there was a lot more--I had a lot greater understanding of the exception for family members than I did before the hearing, and so that suggests to me that this guidance, which I think is good, it is not the letter that everyone has been talking about because the letter deals with serious and imminent threat. This is guidance about what can be shared with family members because often patients, in fact, want their information to be shared with one or more of their family members or a close friend who is helping to care for them, and yet it doesn’t happen. And it could be made more clear, frankly, and we could
find better ways of disseminating this guidance. I mean, I know where it is on the website, but there is probably lots of folks who can’t find it, who aren’t aware that it exists, and particularly when faced with a person and a healthcare facility telling them, which is probably something that they unfortunately believe, that HIPAA won’t allow that information to be shared, when, in fact, it does.

I am happy to answer any questions, and I appreciate the opportunity.

[The prepared statement of Ms. McGraw follows:]

*************** INSERT 8 ***************
Mr. {Murphy.} Thank you very much. We thank all the panelists. I want to also say here that our hearts go out to the families, Mr. Wolfe, Mr. Kelley, and Ms. Thomas. It is sad tragedies and Mr. Kelley, that you are still dealing with here.

I want to— we are going to recognize each person for 5 minutes.

I just want to make it clear, Ms. Levine, you stated you had some opinions in your testimony. You are not a licensed provider, am I correct?

Ms. {Levine.} No, no. We are--

Mr. {Murphy.} And you are not a practicing therapist in this field?

Ms. {Levine.} Not at all.

Mr. {Murphy.} Okay. It is just very important for the record because on page ten of your written testimony you said that doctors don’t want to share information, and it is, "a convenient excuse not to talk to families or listen to what they know about a patient." You went on to say it is, "easier to avoid difficult conversations about prognosis and
1932 treatment options.''
1933 Dr. Martini, is that true that doctors don’t want to
1934 know this, they don’t want to know this information, they
1935 don’t want to talk to families because it is difficult?
1936 Dr. {Martini.} No. I think that the vast majority of
1937 physicians that I work with are very interested in sharing
1938 that information and very much want, I think, to involve
1939 families in care. I mean, I think we know that particularly
1940 for psychiatric patients that their prognosis is approved,
1941 that, I mean, one of the ways I look at it is I see a patient
1942 perhaps at the very most an hour a week, and the families are
1943 dealing with these individuals on an ongoing basis, and I
1944 think any recommendation that I make as a clinician is much
1945 more likely to be successful if I am able to get the support
1946 of the family.
1947 Mr. {Murphy.} Mr. Wolfe, Ms. Kelley--Ms. Thomas, and
1948 Mr. Kelley, just real briefly, just in a word or two because
1949 I don’t have a lot of time, also from your standpoint because
1950 you have also talked to providers about these cases, do you
1951 think in these cases the providers did not want to talk to
1952 you, or they did, but they felt they could not because of
their interpretation of the law?

Mr. Wolfe?

Mr. {Wolfe.} Yes. My family physician told me later that he did want to disclose it, but he felt that he was under the obligation of the HIPAA rules not to disclose it.

Mr. {Murphy.} Mr. Kelley?

Mr. {Kelley.} In 14 years I have never encountered a situation where a treatment provider did not want to disclose it. In fact, they went out on a limb and would secretly tell us. No, I have never had that.

Mr. {Murphy.} Ms. Thomas?

Ms. {Thomas.} I can only speak for what law enforcement told me and also what Mark’s parents have told me about, and they all had difficulty getting information.

Mr. {Murphy.} Thank you. Mr. Wolfe, Mr. Kelley, you heard from Mr. Rodriguez from the Office of Civil Rights that the law, it sounds like he is saying that the law is adequate, and the problem is that providers aren’t really aware of the law and are unjustifiably worried about lawsuits, perhaps even hospital administrators who pressure staff not to disclose information or they will be fired.
Do you think that is true that it is adequate the way it, both the way the law is worded and in terms of the way information gets out to providers?

Mr. Wolfe?

Mr. {Wolfe.} I don’t think it is adequate as far as getting out to the providers because both in my son’s case with the rehab situation as well as my family care physician, both of them after Justin deceased, I confronted them, and they both told me that they definitely would have said something with regard to informing me. However, again, with him signing, with Justin signing the HIPAA disclosure, they were not permitted to. So I do feel that they did have an obligation. They knew that they--his--it was a life-threatening situation with the use of heroin, but they were obliged to follow the HIPAA regulations.

Mr. {Murphy.} Thank you. Mr. Kelley?

Mr. {Kelley.} In all due respect I fear there is a significant detachment from reality here. Not with you, sir, but with Mr. Rodriguez. It is underlined, unless the patient objects, and someone that is really mentally ill universally wants to object. They don’t believe they are ill.
So that gets thrown out the window, and the fact is that we need to have exceptions for the severely mentally ill. It is just plain and simple.

Mr. {Murphy.} Ms. Thomas?

Ms. {Thomas.} I can speak on behalf of the fact that I am a volunteer EMT for our community, and the threat of lawsuit, it prevents us even from feeling like we are able to tell direct family members conditions of patients that we transport. So either it is misunderstanding but that is what is emphasized to us in our training.

Mr. {Murphy.} Thank you. Ms. McGraw, in your written statement you said that 17 percent or about 38 million say they would withhold information from healthcare providers due to worries about how medical information may be disclosed.

You were citing a study.

Ms. {McGraw.} Yeah.

Mr. {Murphy.} My understanding is that study was on general health issues, not mental health or severe mental illness. Am I correct?

Ms. {McGraw.} No. That is right. In the time that I had to prepare for this testimony I looked for some more
specific statistics on, you know, persons being held back from seeking treatment for mental health, and I didn’t have--

Mr. {Murphy.} Sure.

Ms. {McGraw.} --enough time to find something directly on point. I did find something on the National Alliance on Mental Illness website that talked about how about two-thirds of the people with mental illness do not seek treatment for a number of reasons; the lack of knowledge, fear of disclosure--

Mr. {Murphy.} Yes. I appreciate that, and I hope if you find some other studies, could you--

Ms. {McGraw.} Yeah. I would be happy to keep looking.

Mr. {Murphy.} I might also say that--

Ms. {McGraw.} I just ran out of time.

Mr. {Murphy.} --we have folks here also saying that doctors didn’t disclose information, and people are over-interpreting the law, not disclosing it here, and you are saying that perhaps patients are also over-interpreting that it would be disclosed.

Let me ask you this. Could you--something very important. You said it is badly mangled. I think that was
your words. What could be done to clarify law? Do we need legislative language, do we need to cite case law, do we need some clarification from the Office of Civil Rights, more public education? What do we need here?

Ms. {McGraw.} Yeah. Well, so, the badly mangled part is--was the reference to the fact that we had all this testimony about what is really in HIPAA and yet people are being told, in fact, that HIPAA is something that it is not and with significant consequences.

You know, more guidance and better ways of disseminating it so it is not, you don’t have to look really hard for it on a website absolutely is the first step that we should be pursuing here, and ideally that could be done in conjunction with the professional societies who have more effective mechanisms for doing outreach to their members. You know, having read this guidance, I am like, well, it is clear, but it could be made more clear, more examples. In this circumstance you can do X. In this circumstance, you can do Y.

Mr. {Murphy.} Thank you. We will look forward to getting your specific recommendations.
Mr. Braley, 5 minutes.

Mr. {Braley.} Thank you, and I should also note, Mr. Chairman, that Ed Thomas’s sister, Connie Flaharty, is also in the audience today. This has impacted her as well, and Jan, I think some of the things that your testimony brought out is there is this misperception that the issues we have been talking about today are unique to large urban areas with a higher concentration of people who are seeking treatments for severe mental illness. Parkersburg is a town of 2,000 people. Five years ago this May it was nearly destroyed by an F5 tornado, and your husband, Ed, was one of those people in the town who rallied people to come back, put the community back together, and one of the other things that I think is so important about your story is that Mark Becker is someone you and Ed knew very well.

Ms. {Thomas.} Exactly. Yes. He was a member of our community. We have known him his entire life and his parents, and I know their frustration in getting him treatment, but there again, I agree with what they are saying. When it comes to severely mentally-ill people, you can’t classify them with someone that has cancer or hepatitis.
or those kinds of things because their thinking is just not rational, and I think there maybe needs to be some exceptions to those rules there.

Mr. {Braley.} Well, and one of the other things that we know is that from the stories that have come out, you and Ed went to the same church as Mark Becker’s parents. So it wasn’t like this was a stranger in your family, and I know that the Becker family has expressed some of the exact same frustrations as parents that we have heard from the other panelists in trying to get Mark the help he needed so that he could put his life back together, and I think that is one of the most disturbing things about this topic is these are stories we hear over and over and over again, and it points to a breakdown in our ability to get people who need it the services that they need in communities all over this country.

But one of the things that I am really interested in is how this particular tragedy in your life has changed how people in your community think about the problems we have been talking about.

Ms. {Thomas.} Well, it is hard to speak for other people, but I do think there needs to be more awareness of
mental health. I think there needs to be--this needs to be expanded on quite a bit. I don’t think there is enough resources out there for people. I think the fact that no one knew that Mark was released and a threat was very frustrating to people. I mean, there were a lot of victims involved. It wasn’t just our family. Those young kids were 14 and 15 years old that witnessed their coach getting shot down at close range in cold blood, and it all could have been prevented, and I think that is a big frustration for a lot of people. They are just--he was not able to get out of harm’s way, and he was loose on the streets just because he wanted to be.

Mr. {Braley.} Well, I think one of the other things this points to is I lived with somebody with a severe mental illness 40 years ago, and I remember the stigma attached to mental illness then, and I think we would like to think that we have come a long ways as a society in dealing with mental illness--

Ms. {Thomas.} Uh-huh.

Mr. {Braley.} --as something that is just as real and impacts people’s lives as much as other diseases, but I think
the reality is that there is still a lot of stigma attached
to it. We like to avoid having these conversations unless it
is impacting us personally. So I want to thank all the
panelists for having the courage to come share your stories.
I know that it has been an incredible challenge for all of
you.

And one of the things that I talked about earlier is
this challenge that family members have with adult children
of being able to have a role in making decisions about their
care when there are sometimes obstacles, and Dr. Martini, you
talked about this a little bit, and one of the questions I
had raised earlier was whether this risk to self or others
standard is still a viable way of getting patients the help
they need for a truly effective treatment. You gave examples
of both sides of the story; one where a family’s intervention
was counterproductive, one where the need for family
intervention was not provided that could have been in the
best interest of the patient.

So how do we resolve this?

Dr. {Martini.} Well, I think, Congressman, what I would
like to do is think about what you last referred to, what is
in the best interest of the patient, what do we think is going to help the patient most, help them in their recovery. I understand that there are issues around the release of information and confidentiality, and I understand that patients are sensitive about that, but what we are talking about is not a release of information generally out to the community. What we are talking about is thinking about particular cases, looking at those cases on a more individual basis, and deciding if this patient is going to do well, what is going to be necessary, what kind of information needs to be shared, should that information be shared with family members, are they an asset in this particular case, and can they help out this individual? Would it be a good idea to share the information with the primary care physician in their community who quite often coordinates care in a variety of ways. That is also an asset that quite often is not part of the process in some ways because the patients are reluctant to have any local connection know much about what is going on with them.

Mr. {Braley.} Thank you.

Dr. {Martini.} So it is what is in the interest of the
Mr. {Murphy.} Thank you. Mr. Braley, that article you referenced before from Sports Illustrated, would you submit that for the binder so it is in the record as well?

Mr. {Braley.} I would be happy to.

Mr. {Murphy.} That has got to be tragic for all the reasons someone would be on the cover of Sports Illustrated, that has got to be the saddest. It is. Thank you.

Now recognize for 5 minutes the gentleman from Virginia, Mr. Griffith.

Mr. {Griffith.} Mr. Chairman, if I could pass at this time, I would appreciate that.

Mr. {Murphy.} We will do that. We will go to Mr. Johnson for 5 minutes.

Mr. {Johnson.} Thank you, Mr. Chairman. First of all, panel members, I would like to reiterate thank you so much for being with us today and for your testimony. I know these are very tough testimonies to give, and our hearts go out to you.

Ms. Levine, you suggest that healthcare workers sometimes use HIPAA as an excuse not to share information and
not simply because they are afraid of fines or sensors. Why else would someone withhold information from inquiring family members?

Ms. {Levine.} Well, because the role of the family member in the care of someone who is, as I said, my, most of my experience is with older adults, although I personally was the family caregiver for my late husband for 17 years. He had a traumatic brain injury and was quadriplegic. So I have my own experiences with this system.

But family members ask hard questions. They want to know a lot of information about why did this happen, what should--what can I expect, why are you giving this medication when it is on the list that says this is contraindicated. I can’t tell you, and this is not to disparage the nursing profession because they are fabulous, but I have had so many nurses say to me, are you trying to tell me how to do my job? Okay. Yeah. I think I am because my husband should not have this medication and that medication together.

So there is a kind of--I can’t tell you how many physicians, nurses have said to me, family members, they are pests, they are nuisances, and they are. I mean, I am not
denying that because they ask the hard questions. The patient in the bed is in pain or is sedated, not going to be a trouble.

Mr. {Johnson.} Okay.

Ms. {Levine.} So it is, I think it is a truth universally acknowledged that family members are important on the day of discharge, take--get them home but not necessarily in the course of a hospitalization.

But I really think that the HIPAA scare, and I am now concerned that there is now going to be a high tech scare because I am already getting emails from vendors saying, we are going to protect you from these horrible audits that are going to happen, and if you only you hire us, you know, you will be safe.

Mr. {Johnson.} Oh, yes. Every time there is a new government regulation an industry crops up--

Ms. {Levine.} Yeah.

Mr. {Johnson.} --around, providing services.

Ms. {Levine.} And, so, I mean, it is not one thing. It that things support each other--

Mr. {Johnson.} Okay.
Ms. {Levine.} --is my feeling.

Mr. {Johnson.} Let me quickly go to several other questions.

One of your recommendations has been for OCR to reinforce to healthcare providers the provision in HIPAA that permits disclosure of relevant information, protected health information to family caregivers or others who are going to be responsible for providing, managing, or paying for a patient’s care. How do you suggest OCR go about doing this?

Ms. {Levine.} Well, I think throughout--and I agree that the website is one way but not the best way. I think that there can be involving the medical professions, involving the people, the risk managers who are doing a lot of the training, involving the leaders and saying, this is not good patient care. We are concerned about hospital readmissions. One of the reasons people come back from the hospital, to the hospital in 30 days and cost Medicare tons of money is that the family members who are responsible for that care don’t know what to do.

Mr. {Johnson.} Okay.

Ms. {Levine.} So they bring them back.
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Mr. {Johnson.} Do you have recommendations for CMS as well?

Ms. {Levine.} Yes. CMS should definitely encourage the--as part of the conditions of participation in Medicare and Medicaid to make sure that the training that they are responsible, accountable for training the hospitals and other--and nursing homes to train their staff in a balanced way, and one more thing which I didn’t get a chance to say.

Mr. {Johnson.} Quickly. I am running out of time but go ahead.

Ms. {Levine.} Just quickly. We asked--when we encounter through our contacts with providers, patients who object to having a family member involved, it has nothing to do with privacy. It has to do with I don’t want my--I don’t want to worry my daughter, I don’t want her to--

Mr. {Johnson.} Okay.

Ms. {Levine.} --have any responsibilities. It is not the privacy.

Mr. {Johnson.} Got you. Okay. Mr. Kelley, you have observed that a clear culture of fear pervaded one of the facilities your son was admitted to. How does this culture
of fear impact decision making by those healthcare workers
and facilities tasked with taking care of your son?
Mr. {Kelley.} And it is more than one hospital, sir,
but essentially we are not in a position to prevent horrific
things from happening, and we have had some candid
discussions with staff and doctors in multiple hospitals,
where they all acknowledge that they are, they use the word,
our hands are tied, due to the HIPAA privacy rules. And so
we try to go further and emphasize the inability of the
patient to take care of themselves and make good decisions,
and it doesn’t phase them.
So what happens is the patient gets mistreated actually,
and so our son has come home and been on the wrong medication
and has been in a horrible condition. So it is pervasive.
It is not just isolated in one situation.
Mr. {Johnson.} Thank you. Mr. Chairman, I yield back.
Mr. {Murphy.} Thank you. The gentleman’s time has
expired.
Ms. DeGette for 5 minutes.
Ms. {DeGette.} Thank you very much, Mr. Chairman, and I
would like the panel to know that I have read all of your
testimony even though I wasn’t here to hear you say it, and for those of you have lost loved ones, my deepest condolences. I know, as I said in my opening statement, I know how difficult it is to have a child with a severe illness. My child has a physical illness, not a mental illness, and she is now a freshman at college. So I know what you have been dealing with in terms of—and Dr. Martini, I know what you were talking about in your testimony, too, of the parents paying the college, you know, the college tuition, parents obviously love the child and are deeply concerned, and yet the child is over 18, and they are wanting to become independent, and they do have privacy issues. It is a really hard balance especially when you are dealing with some of these mental illnesses which as we learned in our previous briefings in this panel from professionals, bipolar disease manifests, which is at the root of some of the violence, most notably suicides, that evidences itself in young men between the ages of 18 and 25 and in young women at a slightly older age. But this is right at the age where they are becoming independent from their families, and most of the time they are over 18.
So it is a hard balance because on the one hand it is like Ms. McGraw was talking about, you want these young people to not feel the stigma so that they will get medical treatment and on the other hand as parents we want to know if they are at risk to themselves or to others, and so it is a balance.

Dr. Martini, something you said just a moment ago really struck me, which is, you know, in trying to grapple with this issue you said that we need to look at the individual. The doctor, we need to rely on the doctors to look at the individual cases and to see if this is a situation where having parental involvement or involvement of another responsible adult would be appropriate to let them know. And I guess I agree with that, but I guess I also in listening to the testimony of the last panel would—that is exactly what they were saying. What they were saying is in their interpretation of HIPAA that is exactly what medical providers are allowed to do.

And so I think what we need to do is we need to—providers need to understand what their abilities are under HIPAA. Wouldn’t you agree with that?
Dr. {Martini.} I mean, I think that that is a very important part. I think educating providers about HIPAA also in a way that makes it seem like this is more of a collaboration that--

Ms. {DeGette.} Right.

Dr. {Martini.} --there is information to be gained. I mean, for example, the State of Tennessee has created a review panel of physicians that can look at cases and can override aspects of HIPAA if that panel, and it is an objective panel--

Ms. {DeGette.} Right.

Dr. {Martini.} --decides that this particular situation is worthy of that, and I think those kinds of initiatives where HIPAA is seen as not simply a government regulation--

Ms. {DeGette.} Mandate. Yes.

Dr. {Martini.} --but as a process, as something that they can participate in, I think the outcome would be better.

Ms. {DeGette.} I agree with that, and if we still have our HHS witnesses here, yes, we do, some of them, is I think we should also have our federal agencies work with the colleges because a lot of these problems seem to come with
the colleges trying to balance the important privacy protections for their students and also letting parents know. And, again, I think they would have some leeway, but we would have to work with them to let them know that.

Dr. {Martini.} I think it is a very good point.

Ms. {DeGette.} Okay.

Dr. {Martini.} I think there would also need to be some help for them because coordinating mental healthcare for students some thousands of miles away would be a challenge.

Ms. {DeGette.} And this goes to my--the last thing I want to talk about because it is not just the HIPAA issues. It is also access to treatment, and I think some of you have probably seen this in your communities. I had--I was actually at the eye doctor, and the assistant came in, and she said she had a 19-year-old son diagnosed with bipolar, and he had become violent. He was--he actually put himself into a 72-hour hold and then he was released, and he actually, you know, involved his parents, and they were involved with it. They couldn’t find any mental health treatment for this kid in Denver, Colorado, and this is another issue as well is, you know, once you diagnosis this,
you have got to be able to find treatment. I think, Doctor,
you probably agree with that.

Dr. {Martini.} Absolutely. I think work force is a big
issue, certainly in pediatric mental health services--

Ms. {DeGette.} Yes.

Dr. {Martini.} --and also I think, I kind of alluded to
this a little bit, we also need to work on access through
primary care. I mean, the thing to remember is that a
majority of the mental health problems are actually treated
by local physicians in the community, and we need to work
with them, we need to help them, we need to educate them so
that access begins locally.

Ms. {DeGette.} Thank you. Thank you, Mr. Chairman.

Mr. {Murphy.} Thank you. I now recognize the gentleman
from Virginia, Mr. Griffith, for 5 minutes.

Mr. {Griffith.} Thank you, Mr. Chairman. I appreciate
your patience.

Let me follow up on that. I think, Dr. Martini, you
were talking about local health professionals being involved
and trying to make sure people get treatment. Is it your
opinion or what are your thoughts, can HIPAA also stand in
the way of proper communications between, for example, the

treatment mental health professional and a patient’s general
care physician?

Dr. {Martini.} I think that there have been cases that I have worked on where the family, the patient does not want the local physician to know about the extent of the psychiatric problems in part because the local physician is in the community, knows a great many people. I think that a good bit of that anxiety is misplaced on the part of the patient, but I can understand it. I also think that what we need to do is we need to work with these local clinicians and physicians to involve them more in mental healthcare to educate them to make them part of the mental health system so that families recognize that the help that they provide is going to be in the patient’s and the family’s best interest.

Mr. {Griffith.} Because one of my concerns that we heard from a previous hearing was it takes--or informal hearing but it took 18 months for the average person with a mental health problem to, you know, get to see a mental health professional, and that is of concern and something that we need to address, but it would seem to me that your
A primary care physician might be in a position to shorten that time period just by making the referrals or by saying this is not such a big deal, and when it is a trusted family physician, a lot of times they can be helpful in that regard. Also in following up, if the professional is not in the immediate community, I represent a rural area, so the mental health professional may be, you know, the next community over, 30, 40, 50, 60 miles, maybe more, and if they can then communicate with the local healthcare provider, it does create some benefits there.

From the perspective of the patient, why do you think such communication, free communication between the healthcare providers is important?

Dr. {Martini.} I think that on the part of the patient what it will allow them to do as you were pointing out is receive services, I think, more efficiently. I think that the local practitioners understand the community, understand what is available in the community, what is available not simply from the standpoint of medical services and mental health services but also within the community, within schools. They are familiar with that. I think that our--
what we need to do as mental health professionals is we need
to work with them to teach them what they can do, to get them
comfortable with what they can do in their practices, and
also to teach them when they can, when they should refer to
us, and then as part of that we need to be available. We
need to make ourselves available, and that is a big question.
We do need to increase the size of our workforce but also we
need to do this in a much more efficient and effective way.

Mr. {Griffith.} Thank you very much.

Ms. McGraw, I noted in your testimony that the fear of
liability for violating HIPAA’s provisions coupled with
misunderstanding of its provisions can be a recipe for not
sharing.

Ms. {McGraw.} Uh-huh.

Mr. {Griffith.} And I am just wondering if you are
familiar with and I hate to ask Ms. Thomas, but I would ask,
are you familiar with suits that go the other way, where
permission could have been granted. I mean, in Ms. Thomas’s
case, you know, the police asked to be notified, he clearly--
the police had made a determination he was dangerous to the
community, they didn’t want him out of on the streets, the
hospital then used HIPAA as a shield to say, oh, well, we
couldn’t tell the police anything.

So I am just wondering if you, Ms. McGraw, have heard of
any suits, and Ms. Thomas, did you all even consider suing
them for letting this dangerous person back out on the
streets when HIPAA would have allowed it?

Ms. {McGraw.} So I can tell you that HIPAA does not
actually have any provisions that enable anyone to sue on
enforcement of it. So either a patient in terms of privacy
rights or someone else in terms of sort of over-
interpretation. Keep in mind also that HIPAA’s allowance of
disclosures for these reasons that we have talked about is
permissive. It still relies on the judgment of healthcare
providers to make the judgment call about what is in the best
interest of the patient.

Having said that, we need to keep in mind that HIPAA’s
the floor and that there are State laws that may provide
greater protections, and they may medical privacy statutes
that could be used for--to impose liability in those
circumstances.

But I certainly have never heard of anybody being sued
for not releasing information except in the case of
information that a patient asks for that is about them,
because you are required under HIPAA to disclose that
information. You can be held accountable under HIPAA for not
doing so.

Mr. {Griffith.} I guess my concern is is that, and I
was a practicing attorney for a lot of years, but my concern
is is that that is one of the ways people like to hate
lawyers, and I understand that, but that is one of the ways
you sometimes get rectification in some of these cases, not
that the money is important. It can’t bring anybody back,
but it may keep somebody from making that mistake again. I
mean, here we had an individual in your case, Ms. Thomas, who
the police bring in, he has just run his car into the back
of, you know, a garage, he is clearly either a danger to
himself or to others. They bring him in, they want
psychological evaluation because he is a threat to somebody,
and the hospital just lets him walk out even though the
police ask for notification. I can’t think of anything else
that would--and to me that is the classic definition of
negligence, and I am very sorry. If you want to answer you
Ms. {Thomas.} No. It is fine. It was considered as far as looking into a lawsuit, however, we were unable to get Mark’s records due to HIPAA, and we just decided that it probably wouldn’t be—it really wasn’t going to benefit anybody at that point in time to proceed with a lawsuit.

Mr. {Griffith.} And I respect that decision.

Mr. {Murphy.} The gentleman’s time has expired.

Mr. {Griffith.} Thank you. I appreciate it, Mr. Chairman, and I yield back.

Mr. {Murphy.} Recognize Ms. Schakowsky for 5 minutes.

Ms. {Schakowsky.} Thank you, Mr. Chairman.

First of all, I just want to say that I hope in future hearings and other events that we will include testimony and participation from the patient community, and I know that there is some—I know there is a discussion right now—

Mr. {Murphy.} Excuse me.

Ms. {Schakowsky.} --about including testimony--

Mr. {Murphy.} We cannot—we are not permitted to have any outbursts, and I would ask that members not say things that might also provoke some outburst. So I ask the folks
be--just continue on. Go ahead, Ms. Schakowsky.

Ms. {Schakowsky.} Okay, and I know there is some discussion about including written testimony, highly footnoted, into the record, and I would certainly recommend that that be done without much ado.

I wanted to--and let me thank especially the family members who came here with your stories. I know it has got to be very, very hard to do, and it is much appreciated.

So I want to understand the examples that, a couple of examples that you gave. You had a patient, a former patient with a mild form of autism, and eventually his parents went to court against his wishes because they said their son could not care for himself and thus remained dependent, and you conclude, `Unfortunately, the subsequent ruling in their favor was counter to our goals of psychiatric treatment and derailed his progress in therapy.''

So are you saying that that was a bad decision that the son should have been able to do what he wanted to do?

Dr. {Martini.} No. What I was saying was that because the son would not allow his parents to be involved in his affairs, nor would he let them be involved in therapy, so I
couldn’t incorporate them into any of the programming that I was trying to organize, any of the treatment that I was trying to organize, couldn’t involve them in the medications that he was prescribed, and they had serious concerns about how he was going to function. Because we couldn’t negotiate that, because he continued to refuse to allow them to participate, this was the only recourse that they had, it went counter to our therapy because the purpose of the therapy for me was to make him more functional, that my goal was--

Ms. {Schakowsky.} I understand that, but what would--at the point that you are saying if they had been involved earlier and I understand that, but at the point of someone making a decision, an adult making a decision about what they want to do, is there--I am trying to understand what a better outcome might have been and could it have been done without going--having to go to court.

Dr. {Martini.} I think that is one of the reasons I put it in there is because I was searching for another way to have a better outcome without having to go to court. If there was a mechanism, for example, similar to the thing I
mentioned in Tennessee where there was an opportunity to
appeal or to present the case in front of a review board
involved in HIPAA to say that is what is going on in this
case, I think it is in this individual’s best interest to
have the parents involved, to have them actively participate
because I think it is more likely that this individual is
going to be successful. His treatment is going to be
successful, and his life, I think, is going to be less
traumatized. If you have an opportunity to do that and there
is a means to modify what is happening with the HIPAA
regulations in these particular cases, I think that it would
be an advantage not just for the family but also for the
patient.

Ms. {Schakowsky.} So you asked the question, if there
is a bias in these situations, should it be towards parental
involvement rather than away from it. What do you conclude?
Dr. {Martini.} Pardon me?
Ms. {Schakowsky.} What do you conclude? If there is a
bias in these situations, should it be toward parental
involvement rather than away from it?
Dr. {Martini.} I think that if there is a bias in the
situation, you know, as a child and adolescent psychiatrist, my bias has been to involve families. We involve families as often as possible in treatments, and I think that for a variety of reasons, and I think if there is going to be a bias in that situation, my recommendation would be that it be toward family involvement, particularly if there are no specific reasons within that family, if there are no contraindications within the family, nothing that would adversely affect the patient.

Ms. {Schakowsky.} Just wonder, I mean, and I am not weighing in on either side, but I think there are people in the independent living community that would feel that a young adult with autism, that there may be some better ways for that individual to live in the community with support, help, et cetera, rather than as you used the word, dependent, at home.

Do you see that as part of the negotiation that might involve everyone?

Dr. {Martini.} Absolutely. I mean, I think in this particular case the goal for this patient was greater independence. What the hope was in treatment was that he
would be able to manage his affairs, that the level of
anxiety that he felt in new situations would go down, that we
would increase the capabilities that he had to manage his
medications. The sense was that having his parents involved,
I think, would have expedited that process.
Ms. {Schakowsky.} Thank you. I yield back.
Mr. {Murphy.} Thank you. Recognize Ms. Ellmers for 5
minutes.
Mrs. {Ellmers.} Thank you, Mr. Chairman, and I would
also like to say to the panel, thank you so much, and I am
going to get emotional, for coming and sharing your stories
because this is the only way we are going to change anything
in mental health, and I know how difficult it is for you to
come forward, but I can just say how much we appreciate your
input so that we can make the right decisions moving forward.
With that I would like to start, Ms. McGraw, thank you
for your comments to my colleague. You know, one of the
areas, again, as a nurse, and Ms. Levine, I completely--I
associate myself with your statements because I think
sometimes it is easier to just give a blanket, you know, hey,
you don’t know what you are talking about. You are the
family member. Anyone who knows better for your family is you. So, unfortunately, that is one of the downfalls of nursing is sometimes we share our opinions a little too openly.

But I am concerned about the misconception of lawsuits because as we know, there are, you know, so many frivolous malpractice lawsuits out there, and this is one of those gray areas where healthcare professionals do not feel that they are protected, and certainly HIPAA violations can be weighed against them, but yet at the same time as far as malpractice, that is not necessarily an avenue that will be taken. Am I correct with your testimony?

Ms. {McGraw.} Yeah. Well, certainly there is nothing in HIPAA that would enable someone to be sued. You know, again, to the extent that you have seen sort of any lawsuits in this space around privacy violations, they are filed under state law provisions.

Mrs. {Ellmers.} Uh-huh.

Ms. {McGraw.} And I don’t, you know, I don’t do malpractice work, but, again, if you are being—if you are facing a malpractice lawsuit, that is a State law action.
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Mrs. {Ellmers.} Perfect. Thank you, and Mr. Wolfe, I would like to ask you a few questions.

Mr. {Wolfe.} Thank you.

Mrs. {Ellmers.} With your situation especially and as sensitive as it is, and, again, I thank you for being brave and sharing that with us. I read over your testimony to find that you were in a situation where you knew what was happening to your son, you knew that there was a drug addiction, and because of that behavior on his part with the, you know, the manipulation that they do so well--

Mr. {Wolfe.} Right.

Mrs. {Ellmers.} --he was able to manipulate and then kind of get his way.

Mr. {Wolfe.} Yes.

Mrs. {Ellmers.} And then you were able to get him into a treatment facility but then you were told that they could not share information with you because of HIPAA. Correct?

Mr. {Wolfe.} Exactly, and the manipulation, the line that goes along with addiction from what I have learned from my son and from others since this has happened was just to give you one quick example, I wanted him to go into an
inpatient treatment program immediately, and he said to me, Dad, I don’t want to go into an inpatient treatment because I don’t want to start using heroin or crack cocaine. And I as a parent had to make the decision what to do--

Mr. {Wolfe.} --and I do my research and I did hear that people do smuggle in--

Mrs. {Ellmers.} Uh-huh.

Mr. {Wolfe.} --heroin and crack cocaine, and there are a lot of other users than Percocet using, which is what he had indicated that he was doing to the family--

Mrs. {Ellmers.} Uh-huh.

Mr. {Wolfe.} --not letting us know that he was doing heroin. So, therefore, the lies and manipulation unfortunately, we sent him to an outpatient which he said he would agree to go to, and when I tried to confront the outpatient counselor for the first couple of weeks I was denied any access to any records or be told why he was there.

Mrs. {Ellmers.} Uh-huh, and I, you know, that, unfortunately, is a story that we continue to hear, and I do agree with you. I do think that there are some changes that
need to be made. More clarifications, I think, than anything so that both healthcare professionals, family members, and patients can all understand a little better what can be shared and what cannot. So I thank you.

Mr. {Wolfe.} Thank you.

Mrs. {Ellmers.} Dr. Martini, I have just about 30 seconds left, but I do want to say just very recently I was at the Partnership for Children in Cumberland County, North Carolina, I represent in the second district of North Carolina. We had a lengthy discussion about mental illness, especially in relation to children. I have a very good friend whose son is autistic and now is starting to show signs of depression and some, you know, beginning signs of mental illness. They are having an incredibly difficult time trying to find the correct physician for him because of his autism that had already been diagnosed.

Quickly, could you just say a few words about that?

Dr. {Martini.} I think that the availability of services is a critical issue. I think at child and adolescent psychiatry we need to expand our workforce not just among psychiatrists but with all child and mental health
professionals. I think we also, as I alluded to before, we need to work with community physicians. We need to work with schools. There are ways to provide services for children locally that can be efficient and effective beyond simply going to a center.

Mrs. {Ellmers.} Thank you so much. I appreciate the Chairman giving me a few more seconds. Thank you.

Mr. {Murphy.} The gentlelady’s time has expired.

Mr. Scalise is next, but I understand he is going to allow Dr. Cassidy to go first.

Dr. Cassidy, you are recognized for 5 minutes.

Dr. {Cassidy.} Thank you, Mr. Chairman, and thank you, Mr. Scalise.

Every one of you, thank you for your note of reality.

Ms. McGraw, clearly we are all concerned about privacy and yet you can respect that there is a certain ambivalence that we must have or that is exhibited by this. So thank you all.

Ms. Levine, the way that you said that the HIPAA laws should be written in something that a patient understands, I put exclamation mark, exclamation mark, exclamation mark
because it is written to avoid liability, not to inform
people of what their rights are.

Now, thank you, all.

Dr. Martini, what a great name for a psychiatrist.

Dr. Martini. I like it.

Dr. Cassidy. I asked Mr. Rodriguez a question, and you put here, if you had a patient who was—if Lithium is still used for bipolar, and if the level is declining but the patient is still compensated, would you feel that current HIPAA laws would allow you to speak to the parent of someone who is emancipated by age or by law that, listen, if this Lithium level goes any lower, they are going to have a psychotic break. This is not an immediate danger, but Mr. Rodriguez seemed to indicate that that would permissible. Would you accept that in your practice that is what most psychiatrists or whomever are doing?

Dr. Martini. If the patient explicitly stated that he did not want that information shared, I think most psychiatrists would believe that they—if the patient was not in imminent danger to self or others, I think most psychiatrists would believe that they should not share that
information.

Dr. {Cassidy.} Now, if the patient had a history of being non-compliant with Lithium and having bipolar episodes and creating some of these terrible heart-rendering stories occurring, would that change the calculus, or would it still be, no, we cannot do it?

Dr. {Martini.} I think that what--when I talk to colleagues of mine about that situation, if they are dealing with a patient that they know is dangerous, if they are non-compliant with their medications, they inform families and significant others, and they take the risk that they may be in violation of HIPAA because they believe that it is in the best interest of the patient.

Dr. {Cassidy.} Now, it is interesting because you say they take the risk, and yet that is a perception and yet some of what we have heard is that that should not be a risk. It should be kind of like, wow, don’t worry. It is not a risk, but it tells me that there is an ambiguity even among people who are full-time professionals. Would you accept that?

Dr. {Martini.} Well, I think that that is true. I think that the problem is is that it is that idea of waiting
until imminent danger. A patient can be non-compliant on medication and for a period of time look pretty stable, and you know that eventually--

Dr. {Cassidy.} Now, not to be rude but we know that there are going to be a pattern of episodes, and so we know, man, he is off his Lithium. I see his level going down. Boom. It is going to happen again. Now, he doesn’t pull a gun, he doesn’t do anything terrible, but he does live under a bridge, he does leave his family, he does sell all his possessions and run down the street, whatever.

In that would there be ambiguity among your colleagues whether they are at risk?

Dr. {Martini.} I think that if when they are seeing the patient, if the patient appears stable and is doing well but they know they are non-compliant with the medications, understanding that mood disorders quite often are episodic, I think that there would be some concern if they told the family but they understand that in many situations they need to do that because the patient has a history.

Dr. {Cassidy.} So, again, there is a perception they are running a risk?
Dr. {Martini.} I think there is a perception that they are running a risk.

Dr. {Cassidy.} Now, Ms. McGraw, Mr. Kelley used the term, I am not quite sure how to pronounce, but I think we are all familiar with it if we have a teenager. On the other hand, his is far more dramatic than that. A year of no insight. Now, this gentleman, his son said that his parents could not know his history, and yet he had no insight. We are not quite sure how to address that. What would you suggest?

By the way, I was also struck as smart as you are and you are an expert in privacy, you learned something from Mr. Rodriguez’s testimony. I will tell you, an ER physician seeing 20 patients a night who is not in your specialty, not hearing this testimony, there is no way that ER physician, there is no way that she can actually be as facile with this information that we are demanding.

What suggestions would you have as to regards of Mr. Kelley’s son?

Ms. {McGraw.} Well, so one of the things that we have had a lot of conversation about and when I said that I
learned something from Director Rodriguez this morning was how the concept of incapacity plays in the capability to share information with family members, which is not contingent on serious or imminent risk but circumstances under which a mental health professional can make a judgment about talking to a family member when they believe it is in the best interest of the patient, which is in circumstances when the patient is not around to object or in incapacity. And, you know, in sort of looking through the guidance that is right in front of me about the ability to talk to family members, the issue of this incapacity which is, in fact, in the regulatory language, it is not really explored in very much detail. So it does leave a lot of uncertainty on the part of providers about how they are--you know, how do they comply with that and what does that mean, and it certainly would be helpful to have the guidance explore that issue in a little more detail in my opinion.

Dr. {Cassidy.} Thank you very much. I yield back, and thank you, again, Mr. Scalise.

Mr. {Murphy.} Thank you. Mr. Scalise, you are now
Mr. {Scalise.} Thank you. Thank you, Mr. Chairman, for having the hearing, and I especially want to thank those family members who have been impacted by mental illness for coming here and sharing your stories with us. We had I thought a real helpful forum back on March 5 where we had some other family members, including Pat Milan, who is from my district, whose son, Matthew, took his life, we being treated for mental illness. They, you know, they actually thought they were making progress. Both Pat and his wife, Debbie, were trying to get information from the doctor, from the treatment centers, and were not able to get that information, and HIPAA was being thrown up as the reason that they couldn’t get access. It turned out after the fact, unfortunately, after he took his life, that in his file he had actually authorized his parents to have access to information, and so it was just incredibly frustrating, angering, you know, for us hearing this at the forum that we had but especially to them as parents who were trying to get the right kind of help for their kids, for their son, and just couldn’t get that access.
And so when we hear these stories, and I know, Ms. McGraw, you talked about it, Ms. Thomas, that people hiding behind HIPAA when it turns out that HIPAA really may not be the impediment. How do we get some clarity in HIPAA to remove this gray area, if it is even in fact gray, that is stopping vital information from being shared with family members, you know, and even in cases where these patients want their parents to have that access, and yet it is being denied.

If, you know, anybody from Dr. Martini and maybe go across. If we can try to figure out what is this disconnect that is stopping this information from being shared when the law by many people’s own interpretation doesn’t preclude that information from being shared.

Dr. {Martini.} I think the thing that is missing in these situations is a discussion of the clinical presentation and looking at these cases on a much more individual basis and providing within the law some flexibility for whether it is appeal or whether it is involvement by clinicians so that there is an opportunity for a psychiatrist, a psychologist to present the case to an objective body to make a request for
modifications in HIPAA in those particular situations.  
Again, thinking about what is in the patients’ best 
interests and to have that objective body rule on that 
process I think somehow making it feel as though this is not 
simply the government telling people what to do, but it is 
the government giving people an opportunity to protect their 
rights but also to ensure the patients get the best care 
possible.

Mr. {Scalise.} Ms. Levine?

Ms. {Levine.} I think we need to start with medical 
education, nursing education, and all other kinds of 
education to have objective people presenting the rules of 
HIPAA, what is permissible, so forth, not the risk managers.

I am sorry if anybody here is a risk manager, but I think 
people, I think this perception of the legal liability, yes, 
anybody can sue anybody for anything, but the real risk is in 
the security of the electronic data, and that seems to have 
been ignored in all of this HIPAA scare. The Washington Post 
did a--

Mr. {Scalise.} And I apologize. I have only got a 
minute left, and I want to get to the four remainder--
Ms. {Levine.} Yeah. So I think we need to do the education in an objective way, balanced way, and think about the patients’ best interests.

Mr. {Scalise.} Thanks. Mr. Wolfe.

Ms. {Levine.} Definitely include the family.

Mr. {Wolfe.} Yes. I just want to say that I feel that the parents, it is very important for parents to be apprised of what is happening with their children, even when they are legally emancipated, and I think that is important to be put into because of the Obamacare since we do take care of them until the age of 26 under our insurance, I would not have lost Justin if I was made aware of what he was going in for. So I think the parents have to be made aware. We are the best caregivers with regard to our children, and there has to be an exception with regard to that.

Mr. {Scalise.} Thanks. Mr. Kelley.

Mr. {Kelley.} I would like to ask that the committee start expanding the definition of a family member beyond a parent because there are other members of the families that are in these roles, but quite frankly, change is hard, and I want to thank Ms. McGraw from the bottom of my heart because
it is taken so long to hear what she just said. We need to change things, and sometimes you can’t get change unless you change things. There has got to be a carve out for the severely mentally ill or this unless the patient objects clause will rule the world.

Mr. {Scalise.} Thanks. Ms. Thomas.

Ms. {Thomas.} I guess I would kind of agree with what he said. I think we need to be made more aware of what HIPAA actually does prohibit, and I do think there probably should be some special clauses there for the mentally ill.

Mr. {Scalise.} Thanks. Ms. McGraw finally.

Ms. {McGraw.} Yeah. Lots more guidance, clear, understandable, disseminated to places that people can easily find it, maybe in a hotline for questions.

Mr. {Scalise.} Thank you, Mr. Chairman. I yield back the balance of my time.

Mr. {Murphy.} The gentleman’s time has expired.

At this time we have finished the testimony. I just want--I understand that the Ranking Member has a unanimous consent request. I do want to say this.

This committee has a practice of only accepting sworn
testimony. We are going to be asked to accept a letter
signed by a number of organizations which states in its first
paragraph that they are submitting a statement for the record
in advance of the hearing. I want to say that we only became
aware of this at 7:15 this morning, and we have not had time
to fully review this statement. In this case it is not a
letter but as I said before, a, ``statement for the record,''
which does not follow the tradition of this committee for
sworn testimony.

Moreover, this is a point of personal privilege for the
Chairman. One of the groups who have signed this letter for
the record has repeatedly circulated false statements about
the Chairman and Ranking Member and have repeatedly and
purposely misrepresented the serious and important work we
are doing here on behalf of patients, families, healthcare
providers, and the public. They have repeatedly and
deliberately misrepresented the committee work with the false
statements.

Thus, in this case submitting a statement for the record
without it being sworn testimony is of concern to the Chair,
and I yield to the Ranking Member for her statement.
Ms. {DeGette.} Thank you. Well, Mr. Chairman, I would ask unanimous consent to place a letter dated April 25, 2013, about the position of these organizations regarding HIPAA. It is signed by the American Civil Liberties Union, the Autistic Self-Advocacy Network, and the Baseline Center for Mental Health Law, and I would ask unanimous consent to put this in the record as the opinion of these organizations.

As we have discussed before, I have been on this subcommittee now for 16 years, Mr. Chairman, and it has always been the practice of the committee to take testimony under oath, and you are absolutely correct that this letter obviously in not under oath. It has also been the practice of this committee, though, to get extensive information from folks who might have expertise or opinions or otherwise, and I have seen this happen numerous times from both sides of the aisle. Simply accepting a document into the record does not necessarily imply agreement with the position stated in that document by either the Chair, the Ranking Member, or any other member but rather it helps to give a more full picture of what people think.

But I agree with you. I do not consider this April 25
letter to be testimony or to substitute for testimony. I believe that it is a statement of that group, and we have done that. I have got many examples here I could give, but in the interest of time I won’t. I simply ask for the Chair’s comity in putting this in and look forward to working with you so that we can clarify documents that will be put in in the future.

I would also note we also did put an article from Sports Illustrated in the record today. So it seems to me this letter would be appropriate.

Mr. {Murphy.} I thank the Ranking Member, and out of my respect for the Ranking Member and understanding some of the unique circumstances of this in this case for the unanimous consent we will accept this into the record at this time, and the majority will also put a statement in along with that.

[The information follows:]

*************** COMMITTEE INSERT ***************
Mr. {Murphy.} I do want to thank the panelists today in continuing our series to deal with this critically important issue for the American people. Not since John F. Kennedy was President I think have we had such a focus on the issues of mental health and mental illness in this country.

Your statements today, the passionate statements from the family members, and, again, our sympathies and our prayers go out with you, the expertise, Dr. Martini, Ms. Levine, and Ms. McGraw, and those in our first panel, I ask that you stay in contact with us. We have a great deal of respect for what you have given to us today and look forward to working with you.

I would like to also add this. I am very proud of the committee members on both sides of the aisle. I think that the members here have shown an absolute dedication to working on this. The statement we had earlier today, there is something like 38,000 suicides, 700,000 emergency room admissions for people who have attempted harm to themselves, and all the issues involved, this committee is focused more than any other subcommittee I think in Congress in our memory.
has worked on this, and I deeply thank the Ranking Member for her compassion and her passion in this. I also thank Mr. Braley for his bringing Ms. Thomas in today.

Again, thank you all very much. I would like to say in conclusion I remind members they have 10 business days to submit questions to the record. I ask the witnesses all agree to respond promptly to any questions we forward to them.

With that this committee is adjourned.

[Whereupon, at 11:35 a.m., the subcommittee was adjourned.]