

**Opening Statement of the Honorable Tim Murphy  
Subcommittee on Oversight and Investigations  
Hearing on “Does HIPAA Help or Hinder Patient Care and Public Safety?”  
April 26, 2013**

*(As Prepared for Delivery)*

Last month, I convened a bipartisan forum to address a difficult, painful, and much-ignored topic: severe mental illness and violence. At our forum, Pat Milam told us about his son, Matthew, who had paranoid schizophrenia. For years, Matt suffered before taking his own life at just 22 years old.

During that forum, Mr. Milam explained that his son’s doctors were unwilling to share concerns about Matt’s high risk of suicide. Mr. Milam believed that the inability to receive and discuss crucial information because of HIPAA was a contributing factor in his son’s death. Another witness, Liza Long, dreaded the difficulties she would face trying to remain involved in her own mentally ill son’s care once he turns 18 due to privacy restrictions in HIPAA.

I’ve been convening regular public forums in my district to discuss the state of our damaged mental health system. At each discussion, parents testified about the HIPAA-created challenges they experienced in getting the best care for their young-adult mentally ill children. As I have just mentioned, in some of these cases, the outcome was tragic.

In 2002 my constituents, Charles and Debi Mahoney, lost their son, Chuck, to suicide. The warning signs were there. Chuck struggled with severe depression. His fraternity brothers, his ex-girlfriend, and college therapist all knew he was in danger and warned the college. But college administrators said federal privacy laws prevented the school from notifying Chuck’s parents about his condition. As the light was chased from this young man’s heart, those who were in a position to help did not.

The stories of the Mahoney’s, the Milam’s, and those we will hear today compel us to act with care and compassion as we develop ways to overcome institutional barriers to quality mental health treatment.

Ultimately, parents may be in the best position to help children suffering from significant mental illness by providing emotional support, medical history, and coordinating care with various mental health professionals.

Today we will examine the ways in which federal privacy laws, beginning with whether HIPAA, applied properly or improperly, interferes with the quality of patient care or compromises public safety or both.

To be sure, HIPAA’s obstruction of health information-sharing between provider and family in no way is limited to mental health. Some of our witnesses will testify that a widespread misunderstanding of what HIPAA says can prevent individuals with serious long-term medical conditions from obtaining appropriate care.

HIPAA, as initially conceived and enacted, reflected an effort to replace a patchwork of state laws and regulations impacting the confidentiality of medical information. From the start, HIPAA was accompanied by considerable anxiety on the part of providers, or the “covered entities.” Fearful of new penalties for violating HIPAA, doctors and nurses were refusing to even talk about a patient’s illness with caretakers, all of whom were caretakers, spouses, siblings, or those managing the affairs of their elderly parent.

Unfortunately, “if you want to be safe, don’t tell anyone anything” became the prevailing attitude at the expense of the patient.

HIPAA has implications that go beyond healthcare into the arena of public safety. According to data from the Government Accountability Office, the records of 1.5 million people who have been either involuntarily committed to mental health treatment, or deemed mentally incompetent by a court of law, and are

therefore prohibited from owning a firearm, are missing from the National Instant Criminal Background Check System, also known as NICS.

Many states have said confusion over HIPAA has prohibited them from sharing these records with FBI and helping to keep firearms out of the hands of the violently mentally ill.

I'm encouraged that a letter sent by our committee in mid-February spurred the Department of Health and Human Services to announce last Friday plans to reform HIPAA so states could upload these records into NICS. I appreciate the work on this issue by HHS Office of Civil Rights Director Leon Rodriguez, who will testify here today.

Our goal with this hearing is to peel away the numerous layers of misinformation surrounding HIPAA so that we can ensure patients are getting the right treatment and the public is kept safe. Sometimes this may involve communication with the parents or family of a patient, who often possess unique insight into their loved one's condition. At other times it involves communication with law enforcement, so providers take the right steps to report threats of violence.

To that end, we will be hearing first from Mr. Rodriguez and Mark Rothstein. Mr. Rothstein is a professor of law and medicine at the University of Louisville, and a noted expert on the HIPAA privacy rule. From 1999 to 2008, he served as chair of the statutory advisory committee to the Secretary of HHS on health information policy.

Next, we will hear from a panel of practitioners and family members who will comment on their personal experiences with HIPAA. Dr. Richard Martini is a Professor of Pediatrics and Psychiatry at the University of Utah School of Medicine. Carol Levine directs the United Hospital Fund's Families and Health Care Project, which focuses on developing partnerships between healthcare professionals and family caregivers.

I want to especially thank the family members who are here today — Gregg Wolfe, Ed Kelley, and Jan Thomas. Gregg's son, Justin, who was diagnosed with a mental illness and had a substance addiction, died of a heroin overdose last December. Ed's son, Jon Paul, has had severe mental illness for the last 14 years. These fathers' efforts to obtain the best possible treatment for their sons was repeatedly stymied, in no small part due to misinterpretations of HIPAA by those responsible for their care. Jan's husband, Ed, a beloved high school football coach, was murdered in 2009 by a young man with mental illness. The parents of her husband's killer believe that they were frustrated by HIPAA in trying to understand the full extent of their son's paranoid schizophrenia. To Gregg and Jan, I want to extend our deepest sympathies.

We also have with us today Deven McGraw, Director of the Health Privacy Project at the Center for Democracy and Technology.

This is an important subject, and I look forward to exploring this issue with my fellow subcommittee members at this hearing.

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