

APRIL 26, 2013 TESIMONY OF EDWARD F. KELLEY III
COMMITTEE ON ENERGY AND COMMERCE
CONGRESS OF THE UNITED STATES
HOUSE OF REPRESENTATIVES

Thank you Mr. Chairman and members of the Committee.

For background purposes – my wife and I have been married for nearly 31 years. We have 3 children – two sons and a daughter - two of which were blessed with great health; and one – our middle child – our other son, born with an illness no one should ever have to endure. Since his diagnosis 14 years ago – one of paranoid schizophrenia – my wife and I have sought to become (first) better educated about mental illness – particularly severe mental illnesses; and, have sought to navigate the mental health system to find ways in which to help our son – and others – improve their lives; and – help the families of others who are ill help their loved ones – and themselves. My wife has been on the Boards of three (3) prominent Mental Health Advocacy Organizations; taught classes to help families cope with their loved ones’ illnesses and how to better navigate the ‘system’; and raised monies for these causes.

Those of us who offer to open up our hearts to you – do not do so without considerable thought and apprehension. Not because we are not fully committed to making a difference – but rather because we are often at risk for being exploited by what we say; or, those we love are at risk for being harmed by our speaking up. This is not easy – and we have taken this chance before – and - in one recent situation -my family has been exploited beyond comprehension. At the end of the day, we seek only to help educate those in a position to make a difference– o that my family – and millions of others – have hope.

There is a gaping hole in addressing the needs for the severely mentally ill – and their families. Mental Health Reform has helped immensely with improving the availability of care for the mentally ill. But in doing so has often addressed the needs for the severely mentally ill in the same manner as that what is done for the 80% of those who suffer from mental illness, but are not as ill and/or have far better opportunities to recover. ***The severely mentally ill are far different – and need far different rules – as do their families.*** To not do so is utterly illogical. There are 11 to 12 million people in the US who are severely mentally ill. And if you multiply that ‘times’ the number of people in their family trying to help – well the math is staggering as to how many people are affected by this approach. **Starting with HIPAA.**

To set the stage properly – here are a few items:

1. For over 14 years our son has been hospitalized dozens of times.
2. He has been in ***8 different hospitals – located in 4 different counties and one city***
3. Since our son turned 18 – he has refused repeatedly to allow hospitals and doctors to disclose information to us–whenever he is psychotic–which is normally the reason for his hospitalization.
4. When someone is severely mentally ill – as has been the case with our son - they have an impairment of the brain known as ‘anosognosia’ – which quite simply creates a belief within an individual that they are NOT ill.

5. With this impairment – our son refuses treatment and refuses to allow his medical providers to speak with us or to provide us with any information regarding his status or treatment (if any).
6. We, as parents, try to make contact with his providers, and those providers then ask our son to sign a release authorizing them to share our son’s condition and treatment. His anger is then directed at us for ‘daring’ to put him in the hospital and wanting ‘control over his life’.

Our family – and I believe the families of millions of others who are severely ill – want to take responsibility for their loved one(s). But so much stands in the way of American families – and this role is already a painful, difficult task. Rather than have the support to help us deal with a situation that is *already tragic*, we are furthered stressed because of laws that cannot possibly have been intended to place such a heavy burden on us. We have lost our son to a cruel, horrible mental illness. And each time we try to help him recover, we are blocked in so many directions.

- We have been prevented from getting him timely (or any) treatment because we have no recent medical records to support our case. This delay or lack of treatment has horrific consequences on our son. Even if our son is hospitalized, we find ourselves begging for the opportunity to help him – mostly we cannot. We are not his seen as parents – we are seen as the enemy.
- HIPAA stifles ***accountability***. Who – if not the family – can make sure our loved one is being properly treated or not? We are at the mercy of medical providers who will do as they see fit, because they can hide behind HIPAA. Decisions to treat or not treat; decisions on medication; having the opportunity to understand the history of our son before treating him; these and other important factors are dropped out. Our son is at risk when we are left out.
- When our son was under 18, the hospitals and doctors relied immensely on our input and involvement. We would spend as much time as they requested or needed – giving them any information we could; and they in return would share with us their diagnosis, treatment plan and concerns. At the very least this process gave us assurances that mistakes have the best chance of being avoided, or repeated; and, would give us some sense of peace that he was being taken care of by people who had a reliable reference point for addressing the matter.
- Once our son turned 18, we – his parents – were the enemy. Our son’s delusions included a belief that HE owned our home – not us. He believed he had served in two (2) wars in Iraq and Afghanistan and had been wounded. He believed he had shrapnel in his body from those experiences, and that was the cause of his hospitalizations. He often would believe he was a U.S. Marshall – or a spy – and that we – his parents – were getting him hospitalized so that he could not do his job. He has seen a friend “living” in my wife’s eye – and burned his yearbook to get that person out of her eye. He has told doctors that I have abused him and that my wife was a stripper and prostitute – and that he was traumatized from our actions. He has lived under bridges when he had a nice place to live. He has accidentally set himself on fire falling asleep with a burning cigarette in his hand, on his chest. He has been victimized thru beatings and robbery

because he was incapable of protecting himself. He has been naked in the snow for an extensive period of time – two times in one day! He is so ill – yet – since he became 18 – it has been a nightmare to help our son.

- With us having access to doctor and hospital records – we could have helped each subsequent doctor and staff treat our son - faster and better – or before he was released. Yet – as he is moved around from hospital to hospital – 8 in 4 counties and the city of Baltimore – there is no way to do this – as we are turned down.
- We have watched our son be given medications that are life damaging – because there is no record of what works or does not work. We usually do not know what medication he is being given. So his health is in jeopardy. As we look back now – we see a broken chain of hospitalizations, psychiatric evaluations and treatments that are unknown. Every hospitalization is a new beginning. We have had a judge tell us she will not “institutionalize” our son – when we wanted to get him hospitalized – because we did not have current records to prove he needed same. We have had doctors tell us that we cannot participate in med-panel hearings, in the hospital, because our son has privacy rights under HIPAA.
- We have not known where our son was; what hospital; when he was released; or what was done to him.
- The argument made is that the ill person can be convinced to allow disclosure – and allow the families to help the medical providers. Well that is not the case when someone is severely mentally ill – because they cannot because of their illness.
- The argument is made that the loved ones can give the hospital information. Well – that information may need further explanation, but the hospital cannot ask for it. The information may lack what happened in several prior hospitalizations, because the hospitals would not release anything to the loved ones. In many cases all we knew was he was in the hospital – and that was it. It is not working this way.
- We have been told that a hospital can give notice to a family member – when the loved one is to be released – if the hospital feels the family members are in danger. Well – the hospital is not supposed to release anyone if they feel that person is a danger to themselves or others. How does that work?
- Our son was hospitalized; escaped from a locked unit in the hospital; a search ensued for 4 days; he was caught and brought to another hospital. He was placed on suicide watch; fired his public defender during an administrative hearing; and was completely and utterly delusional. Yet my wife and I were not allowed to testify at a med-panel hearing, because of HIPAA laws. He ended

up spending 1 year in that State hospital – without proper treatment – because of privacy laws and the issues concerning involuntary medication. We were powerless to help.

- We have called emergency rooms to speak with a doctor – and been told – “we cannot acknowledge a person is here in the hospital”. Sometimes a hospital tells us. Other times they do not. We sometimes ‘get around’ the situation by calling the phone in the patients’ sitting area – as patients answer the phone and use it to make calls – and ask patients if (‘name of our son’) is there.
- Our son has been released numerous times without our knowledge. He has been placed in a bus from a hospital 2 hours away – and gone into Baltimore City – and we could not find him for days and days. He has been released and walked out with no money or adequate clothing. We have found him in our garage when we thought he was in the hospital. We have laid awake countless nights wondering if he was being treated properly; or if he had been released and had been beaten, killed or otherwise victimized.
- Often times neighbors or friends would tell us they saw our son – at varying places – when we thought he was being safely treated in the hospital

Communities and people are affected by lack of proper treatment when we families cannot help their loved ones: stress and loss of jobs; damage to the brain of the loved one; damage to the loved one’s heart or nervous system; homelessness; substance abuse; victimization; abuse; medical condition decline; isolation; fear; desperation; suicide.

And these can, and are, the consequences of not allowing those who want to help their loved ones – help their loved ones – because HIPAA says we cannot.

WE HAVE EXPERIENCED ALL OF THESE:

- A. Emergency Room Personnel often times prevents the patient's family from coming into the admitting area at the time their loved one is brought in. If the family member brought their loved one in, they can be denied going into the back area with their loved one. If their loved one came in to the hospital thru an emergency petition, the family member does not usually accompany their loved one. If the loved one came in to the emergency room without the family's knowledge, they have to start calling around when/if they suspect something has happened.
- B. If you know your loved one was taken to a particular emergency room – and you call to provide information you feel is helpful – medication, prior hospitalizations, diagnosis – often the person on the other end of the phone says “we cannot acknowledge that any person is or is not in this hospital. Our agreeing to take information could be construed as acknowledgement the person IS in the hospital.” Or – they say they can receive your information, but the family has NO idea how or if it is being used; especially given the loved one may deny everything.
- C. No ‘system’ is available for providers (hospitals) to access the loved one's (patient's) prior history of mental health hospitalizations – so ‘experiment’ can begin with each admission.
- D. When your loved one is in the emergency room – and the family is prevented from contributing information – several negative consequences can happen:
 - 1. Release without treatment.
 - 2. Provide inadequate treatment by administering medications that do not work or address the symptoms – especially if anger, anxiety, depression, hostility or psychosis are masked by the patient or exacerbated with substance use.
 - 3. Treatment with medications that have already proven to cause harm
- E. During an Administrative Hearing at the Hospital – assuming you are asked to participate:
 - 1. Hospital can elect to ignore family's input and, or prevent testifying
 - 2. Hospital can decide to release the person without understanding the situation more clearly – as they do not have adequate information
 - 3. Hospital can continue to require person to remain in the hospital – but shut out the family from helping them properly treat the patient.
 - 4. Patients can be kept in the hospital for longer periods of time – without any treatment – which is so cruel – because the hospital had inadequate information.

F. Release of Loved One by the Hospital

1. Hospital can determine to not inform family of the release of the person – if they determine the person is not a threat [which they already have (determined the patient is not a threat to self or others) if they plan to release the patient.
2. Family's home is often the place where released person often goes first – and the family is not aware of their pending arrival; or may not even be there when their loved one arrives.
3. If the patient goes somewhere else, after their release, they often are homeless and vulnerable to attack.
4. The family can find themselves frantically trying to locate their loved one.

G. Flaws in the HIPAA System Exist Anyway

1. If the loved one files with the courts - for his/her release from a hospital in which they were involuntarily committed – that filing becomes public record [see at end of this Exhibit].
2. Staff members of the Hospitals sometimes take a personal risk, and tell families 'off the record' what is going on – but that employee may have limited information – so the family gets part of the message.

Example A – Hospital would not acknowledge our son was admitted. We found out because a friend of ours took a chance and called us privately. Hospital did not accept our offer to provide history, medication experience, diagnosis of illness – as our son specifically advised them there was to be no contact with us. A few weeks later – that same person called us to say our son may be getting released soon – and that the staff there had a conversation debating whether or not to advise us to move to an undisclosed location – but decided they could not because of HIPAA laws.

Example B – Our son was admitted involuntarily into a hospital – and the hospital refused to allow us to provide testimony and information regarding his prior history, including his hostility towards us. Our son escaped that hospital, and was eventually caught by the police [quite a dysfunctional situation – hospital felt he was not a danger – so no medication – but once he escaped – four counties and Baltimore city searched together for him. [what was interesting is that the police called to ask if we knew where he was – but not the hospital!!!! We were spending the night in D.C.] He was found after 4 days by the police - and taken to a different hospital - and -despite being on suicide 'watch' – he was

deemed to not be a danger to self or others. When his Med Panel hearing came up – we were not allowed to testify due to HIPAA. THEN – when I demanded that I felt we had a right to provide testimony – they asked me to remain in the waiting room so they could call the Maryland Attorney General’s office for guidance. They came back 30 minutes later and advised me that due to HIPPA, my son could require I not be allowed to testify. When I called the Attorney General’s office the next day – to ask why they had made that decision, they advised me they had NOT spoken with the staff at Spring Grove. SO - Despite our son being in the hospital for a year – and – despite his condition – despite only in the last 4 weeks had they been medicating our son – they did **NOT** call us to advise us he had been released from the hospital. My wife called me while I was in Michigan – to advise me she had found him sleeping in our garage.

Example C – Our son was 19 – and his hospital placement took him out to Washington County, MD – hours away. We could not coordinate anything over the phone – due to HIPAA. Eventually he was released – and placed on a commercial bus and sent back to Baltimore City. It took us weeks to figure out if he was alive or dead – and his condition.

Example D – When our son was being diagnosed for classification as being ‘disabled’, the psychiatrist asked our son if it would be OK if his parents attended their session,. Our son refused. When he went into the adjoining room – he told the doctor he had served in both Gulf wars and had shrapnel in his body – which was causing all sorts of problems. The interviewer believed him!!!

So many times we would have no idea as to our son’s condition at the hospital – as he would refuse to see us – and often when we would go to visit – the staff would not acknowledge whether he was there or not – so we had no idea if he had been released or not. We would lie awake at night wondering where he was – what condition he was in – whether he had been released.

CASE # 1:

Shows he is a patient at Spring Grove Hospital

Case Information

Court System: **Circuit Court for Baltimore County - Civil System**
Case Number: **03C06013732**
Title: **Kelley Vs Superintendent Spring Grove Hospital Center**
Case Type: **Other Civil** Filing Date: **12/27/2006**
Case Status: **Closed/Inactive**
Case Disposition: **Decree or Order** Disposition Date: **01/05/2007**

Plaintiff/Petitioner Information

(Each Plaintiff/Petitioner is displayed below)

Party Type: **Plaintiff** Party No.: **1**
Name: **Kelley, Jon Paul**
Address: **Spring Grove Hospital**
City: **Catonsville** State: **MD** Zip Code: **21228**

Defendant/Respondent Information

(Each Defendant/Respondent is displayed below)

Party Type: **Defendant** Party No.: **1**
Business or Organization Name: **Superintendent Spring Grove Hospital Center**
Address: **Spring Grove Hospital**
City: **Catonsville** State: **MD** Zip Code: **21228**

Attorney(s) for the Defendant/Respondent

Name: **Malone, Esq, Daniel**
Appearance Date: **02/05/2007**
Practice Name: **Office Of Attorney General**
Address: **300 West Preston Street**
Room 302
City: **Baltimore** State: **MD** Zip Code: **21201**

Document Tracking

(Each Document listed. Documents are listed in Document No./Sequence No. order)

Doc No./Seq No.: **1/0**
File Date: **12/27/2006** Close Date: **01/05/2007** Decision:

Party Type: **Plaintiff** Party No.: **1**
Document Name: **Petition for Habeas Corpus**

Doc No./Seq No.: **1/1**
File Date: **01/26/2007** Close Date: Decision:
Party Type: **Defendant** Party No.: **1**
Document Name: **Response To Petition**

Doc No./Seq No.: **2/0**
File Date: **01/05/2007** Close Date: **01/05/2007** Decision: **Denied**
Document Name: **Order for Habeas Corpus**

CASE # 2

Shows our son is a patient at Spring Grove Hospital

Shows he was fighting to get out

Case Information

Court System: **Circuit Court for Baltimore County - Civil System**
Case Number: **03C07013093**
Title: **In the Matter of Jon Paul Kelley**
Case Type: **Administrative Agency Appeal** Filing Date: **11/15/2007**
Case Status: **Closed/Inactive**
Case Disposition: **Lack of Prosecution** Disposition Date: **10/13/2010**

Plaintiff/Petitioner Information

(Each Plaintiff/Petitioner is displayed below)

Party Type: **Petitioner** Party No.: **1**
Name: **Kelley, Jon Paul**
Address: **Spring Grove Hospital**
City: **Catonsville** State: **MD** Zip Code: **21228**

Related Persons Information

(Each Related person is displayed below)

Party Type: **Administrative Agency** Party No.: **1**
Business or Organization Name: **Spring Grove Hospital Center**
Address: **Spring Grove Hospital**
City: **Catonsville** State: **MD** Zip Code: **21228**

Document Tracking

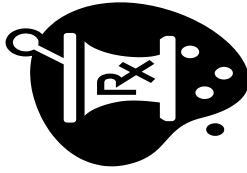
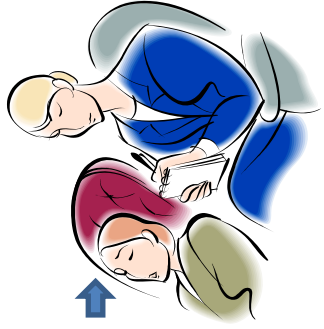
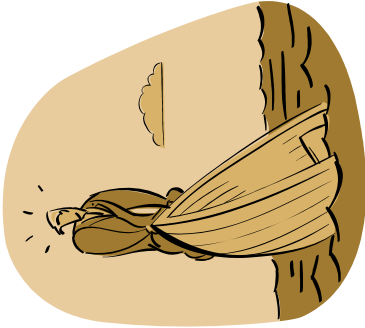
(Each Document listed. Documents are listed in Document No./Sequence No. order)

Doc No./Seq No.: **1/0**
File Date: **11/15/2007** Close Date: **10/13/2010** Decision:
Party Type: **Petitioner** Party No.: **1**
Document Name: **Petition for Judicial Review/Release**

Doc No./Seq No.: **2/0**
File Date: **04/23/2009** Close Date: **04/23/2009** Decision:
Document Name: **Notice of Cont. Dismissal Lack of Pros.**

THE GAP IN TREATING THE SEVERELY MENTALLY ILL – APRIL 26, 2013 TESTIMONY OF EDWARD KELLEY

LOVED ONE STOPS MEDICATION
THE SIGNS OF STRUGGLE APPEAR
THE FAMILY SEES THESE SIGNS

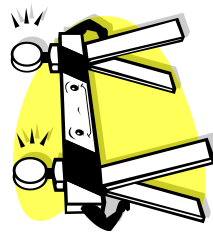


LOVED ONE
Refuses to Get
Help or Counseling,
and Blames Others.

Anosognosia
NOT DENIAL

Paranoia, Delusions,
Fear, Anxiety

[-----] **[THE 'TREATMENT GAP' – ABSENT TIMELY CARE WITH FAMILY HELP – THERE EXISTS RISK TO THE PERSON & OTHERS]** [-----]



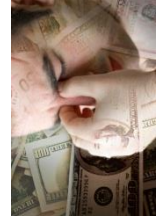
FAMILY SHUT OUT FROM
DR'S - DELAYS TREATMENT



SUBSTANCE USE
TO SELF-MEDICATE



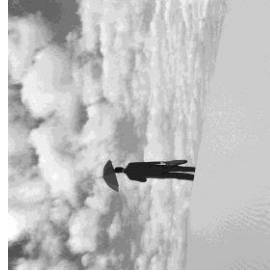
FAMILY CANNOT VISIT OR
HELP WITH TREATMENT PLAN



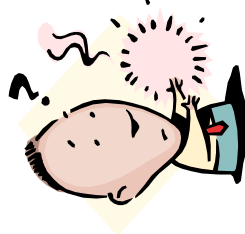
FAMILY SHUT OUT
WHEN LOVED ONE
GETS (IF) HOSPITALIZED



ANGER/FRUSTRATION HE
"DOES NOT UNDERSTAND"



INCREASED ISOLATION
"NO ONE UNDERSTANDS"



FAMILY HAS NO CONTROL



OR TRAGEDY



THE LOVED ONE CAN
BECOME A VICTIM



OR INCARCERATION



DESPERATION
CRIME



NOT TREATED
PROPERLY OR
RELEASED **TOO SOON**