Congressional Testimony

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Good morning, Chairman Murphy, ranking member DeGette and members of the subcommittee. My name is Dr. Richard Martini, and I am currently Professor of Pediatrics and Psychiatry at the University of Utah School of Medicine and Chair of the Department of Psychiatry and Behavioral Health at Primary Children's Medical Center in Salt Lake City. I have been a practicing child and adolescent psychiatrist for over 25 years, and am 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 speak to you about HIPPA and its implications in clinical practice, and to participation in this discussion. Throughout my testimony I will be reviewing patient summaries that are based on my clinical experience, but that do not include easily identifiable information.

Privacy and confidentiality between a physician and his/her patient is paramount. When asked for patient information, physicians should make reasonable efforts to disclose only what is necessary for the purpose requested. However, physicians are required to release medical information, even without the patient's written consent, when they have concerns that he or she may be at risk for immediate harm to themselves or others, and when ordered by a court.

Decisions around the release of psychiatric information are more straightforward when the child or adolescent is a minor and not emancipated. Parents and/or primary caregivers are involved in the process and 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 the extent of the behavioral and emotional problems that affect them, 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 to young adulthood, from a position of dependence to one of complete autonomy. Many are not prepared for the responsibility, particularly those with chronic physical illnesses, developmental delays, and psychiatric disorders. Families have provided a framework for their care and for many aspects of their life. When that framework is removed, some patients believe that this is an opportunity for them to manage their own lives, and to assert themselves apart from parents and family members. A former patient with a mild form of autism, developmental delay, and an anxiety disorder was determined to move out of the home and into his own apartment once he was able to get a janitorial job at a local airport. His parents knew that he could not manage money, reacted emotionally when faced with anything outside of his experience, and was unable to keep track his medications. Nevertheless, he did not want his parents involved in his care, and because of HIPPA regulations, the only way that the parents could address their concerns was by going to court and stating that their son could not care for himself and must remain dependent. Unfortunately, the subsequent ruling in their favor was counter to our goals of psychiatric treatment and derailed his progress in therapy.

Health professions train with an emphasis on HIPPA and its attached liability penalties, and may not practice with the appropriate clinical sensitivity that balances patient and family engagement. 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, application of HIPPA regulations should be a negotiation with several options available to both the patient and the clinician. A patient of mine in his early 20’s suffered from a congenital kidney disease and spent his life in and out of hospitals, with his mother by his side, until her received a transplant in his late teens. I saw him in therapy because he could not accept the changes his illness and the transplantation made in his life, particularly when he compared himself to same age peers. He created stories to explain his scars and was angry and depressed over his situation. I wanted to involve his mother in therapy both as a support and as a source of information to better understand his experience as a renal patient. He refused because he believed that his mother would be disappointed in his behavior given all that they shared together. After a year in therapy with a trial of antidepressants, he dropped out of treatment, finding it too difficult. Two years later I learned from his physician 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 HIPPA, and use the strengths of the family when necessary to support treatment. I recognize that allowing for more communication and less privacy for an adult patient at risk for serious mental illness is a significant change in the intent of the law. 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? The State of Tennessee, for example, created a treatment review team of physicians that can override HIPPA regulations when it is believed to be in the best interests of the patient's health. The challenge is in where and when to draw that line.

Rules about confidentiality affect situations that are relatively common in adolescence and young adulthood, including enrollment in college. When a young adult begins her college education, parents are told that although they will be paying the bills, they will not be given any medical, or psychiatric information about their child without the student's permission. Family members as well as medical and mental health professionals must negotiate with a young adult whose priorities may be very different than their own. One such patient with a history of congenital heart disease, multiple cardiothoracic surgeries, and depression wanted to go away for her college education. Mother preferred that she stay in town, in close proximity to the children's hospital where she received her care. The patient prevailed and enrolled in a small rural college approximately 200 miles from home. Within three months, she began to struggle, not with academics but with her energy level and her depression. She colluded with her older brother who drove to her dorm the day before her parents would arrive and cleaned her room, did her laundry, and organized her schoolwork. The patient knew that if her parents discovered the extent of her troubles, she would be forced to transfer back home. The Student Health Center knew that she was struggling, but could not talk to the parents without her permission. Now imagine that this patient had a history of a serious mood disorder, a substance abuse disorder, or an eating disorder, all with serious consequences. The only indication for the parents that there is a problem may be a bill from the Student Health Center that arrives 30 days after an event. If there is a bias in these situations, should it be toward parental involvement rather than away from it.

Through the Affordable Care Act parents are now allowed to keep their young adult children on their health insurance until age 26. I support this and believe that it will ensure the provision of needed medical and mental health services. However, it is unclear who owns the record and what rights the parents have to their young adults health information. It creates a new grey area in terms of respecting the adult patient who is receiving benefits as a dependent of a parent.

Mental health professionals strive to do what is in the best interests of the patient, while preserving her right to privacy and protection under the law. The basis for 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.