April 25, 2013

Honorable Tim Murphy, Chairman
Oversight and Investigations Subcommittee
Committee on Energy and Commerce
2125 Rayburn House Office Building
Washington, DC 20515

Honorable Diana DeGette, Ranking Member
Oversight and Investigations Subcommittee
Committee on Energy and Commerce
2125 Rayburn House Office Building
Washington, DC 20515

Dear Chairman Murphy, Ranking Member DeGette, and Members of the Subcommittee:

On behalf of the undersigned organizations, we submit this statement for the record in advance of a hearing of the Oversight and Investigations Subcommittee of the U.S. House Energy & Commerce Committee on "Does HIPAA Help or Hinder Patient Care and Public Safety." We strongly urge the Committee not to weaken current privacy protections in the Health Insurance Portability and Accountability Act (HIPAA).[1] Neither patient care nor public safety requires modification of HIPAA, which already contains numerous exceptions to accommodate the interests of the individual and the public. HIPAA carefully balances the privacy right of individuals with disclosure of select information when necessary, such as for insurance or billing purposes, to ensure compliance with HIPAA for public health reasons, or, less commonly, when an individual presents a serious danger to self or others.

As the Committee examines HIPAA in the context of patient care and public safety, we would strongly caution against rhetoric that inaccurately links people with psychiatric disabilities to public safety concerns. This rhetoric will only further isolate and stigmatize the millions of Americans with psychiatric disabilities, which is a step backward after years of breaking down the stereotypes and misinformation about mental illness. Further, such rhetoric may negatively impact patient care by making people with psychiatric symptoms disinclined to seek treatment or reluctant to share full information with their providers out of a concern about reduced privacy standards.

Because this hearing will be addressing the impact of HIPAA on public safety, and this Subcommittee held a forum last month, "After Newtown: A National Conversation on Violence and Severe Mental Illness," we would like to clarify a frequent misconception about psychiatric disabilities and violence – people with psychiatric disabilities are no more likely to be violent than anyone else. Studies show that "severe mental illness alone [is] not statistically related to future violence . . ."[2] In fact, people with major psychiatric diagnoses, such as bipolar disorder

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[1] The Health Insurance Portability and Accountability Act of 1996, Pub. L. No. 104-191, 110 Stat. 1936 (1996).
[2] Eric B. Elbogen & Sally C. Johnson, *The Intricate Link Between Violence and Mental Disorder: Results from the National Epidemiologic Survey on Alcohol and Related Conditions*, 66 ARCH. GEN. PSYCHIATRY 152, 157 (Feb. 2009); *see also* David J. Vinkers, ET AL., *Proportion of Crimes Attributable to Mental Disorders in the Netherlands Population*, 11 WORLD PSYCHIATRY 134 (June 2012) (discussing a study indicating that the proportion of violent crime directly attributable to mental illness is 0.16 percent); Henry J. Steadman, ET AL., *Violence by People Discharged from Acute Psychiatric Inpatient Facilities and by Others in the Same Neighborhoods*, 55 ARCH. GEN. PSYCHIATRY 393, 400 (May 1998) (finding that the prevalence for violence among individuals with mental illness

and schizophrenia, are at greater risk of being attacked, raped or mugged than the general population.[3]

Thus, no public safety benefit justifies singling out and further stigmatizing people with mental disabilities, and this stigmatization comes at a significant cost to these millions of Americans. Psychiatric disabilities are extremely common, as 1 in 5 adults will experience a psychiatric disability in any given year, and about half of the population will experience the symptoms of a psychiatric disability at some point during their lifetimes.[4] Yet, despite the prevalence of psychiatric disabilities, pervasive stigmatization of individuals with mental disabilities continues to deter people from seeking diagnosis and treatment when needed.

Since the enactment of HIPAA nearly two decades ago, its privacy guarantees have advanced public health by re-assuring millions of Americans that their medical records will be private and secure. The end result is better patient care as individuals trust the integrity of their relationships with medical providers, and information is shared freely. The general principle of HIPAA is that an individual's protected health information may not be used or disclosed except as the individual or the individual's personal representative[5] authorizes in writing or as HIPAA permits or requires.[6] The scope of HIPAA extends to all "individually identifiable health information," whether electronic, paper, or oral, held or transmitted by a "covered entity," which include (1) health plans, (2) health care providers, and (3) health care clearinghouses, or their business associates.[7] This information is referred to as "protected health information" (PHI) under HIPAA.[8] Apart from exceptional circumstances, the parents or guardians of minors are typically their personal representatives, and have the right to access their medical records.[9]

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and the prevalence for violence among other residents of the same neighborhoods was "statistically indistinguishable."); Seena Fazel et al., *Schizophrenia and Violence: Systematic Review and Meta-Analysis*, PLOS MED. 6, e1000120 (2009).

[3] John Grohol, *Dispelling the Myth of Violence and Mental Illness*, PSYCHOLOGY CENTRAL (June 1998); John Monahan, *Mental Disorder and Violent Behavior: Perceptions and Evidence*, 47 AMER. PSYCHOLOGIST 4, 511-521 (1992): Claudine Chamberlain, *Victims, Not Violent: Mentally Ill Attacked at a Higher Rate*, ABC News; *see also* Linda A. Teplin, ET AL., *Crime Victimization in Adults with Severe Mental Illness*, 62 ARCH. GEN. PSYCHIATRY 911, 914 (Aug. 2005) ("Over one quarter of the [Serious Mental Illness] sample had been victims of a violent crime (attempted or completed) in the past year, 11.8 times higher than the [general population] rates . . . ."); Heather Stuart, *Violence and Mental Illness: An Overview*, 2 JOURNAL OF WORLD PSYCHIATRY 121, 123 (June 2003) ("It is far more likely that people with a serious mental illness will be the victim of violence," rather than its perpetrator.); Karen Hughes *et al.*, *Prevalence and risk of violence against adults with disabilities: a systematic review and meta-analysis of observational studies*, 379 THE LANCET 1621-1629, (2012), *available at* http://www.who.int/disabilities/publications/violence_children_lancet.pdf; Lisa Jones et al., *Prevalence and risk of violence against children with disabilities: a systematic review and meta-analysis of observational studies*, 380 THE LANCET 899-907, (2012), *available at* http://press.thelancet.com/childrendisabilities.pdf.

[4] *Assessing the State of America's Mental Health System: Hearing Before the S. Comm. on Health, Education, Labor, and Pensions*, 113th Cong. 2 (2013) (statement of Pamela S. Hyde, Administrator, Substance Abuse & Mental Health Serv. Admin., U.S. Dep't of Health & Human Serv.).

[5] 45 C.F.R. § 164.502(g).

[6] 45 C.F.R. § 164.502(a).

[7] 45 C.F.R. § 160.102, 160.103, 162, 164.500(b), 164.504(e), 164.532.

[8] 45 C.F.R. § 160.103.

[9] 45 CFR 164.502(g); *see also* Off. for Civ. Rights, Dep't of Health & Human Servs., *Understanding HIPAA: Personal Representatives*, http://www.hhs.gov/ocr/privacy/hipaa/understanding/coveredentities/personalrepresentatives.pdf (last visited Apr. 24, 2013) (*But see* the exception to this general rule: "When a physician or other covered entity reasonably believes

HIPAA also encompasses adults granting permission for disclosure of their protected health information to family members, friends, or others. Protected medical information may also be disclosed to friends, family, and others involved in the patient's care or payment for the care when an adult patient is not present or unable to give permission (for instance, due to being unconscious) if the medical provider determines that, in his or her professional judgment, it is in the patient's best interest.[10] Individual authorization is also not required to share protected health information with the individual directly, or for purposes of treatment, payment for services, health care operations, or incidental use and disclosure.[11]

Further, HIPAA provides for the disclosure of protected health information without an individual's authorization for 12 "national priority purposes" related to the public interest.[12] Note also that several entities that may possess health information – such as elementary and secondary schools, life insurance companies, and law enforcement – are not subject to HIPAA.[13] Given the breadth of the exceptions from HIPAA's protections and the limited application of HIPAA to "covered entities," multiple avenues already exist for the sharing of protected health information when warranted by public health or safety concerns. These exceptions include:[14]

1. ***When required by law***, including statute, regulation, or court orders;

2. ***Public health activities***, such as the collection of vital statistics, or reporting the exposure to communicable diseases;

3. For reporting of ***abuse, neglect, or domestic violence***;

4. ***Health oversight activities*** (e.g. audits, inspections);

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that an individual, including an unemancipated minor, has been or may be subjected to domestic violence, abuse or neglect by the personal representative, or that treating a person as an individual's personal representative could endanger the individual, the covered entity may choose not to treat that person as the individual's personal representative, if in the exercise of professional judgment, doing so would not be in the best interests of the individual.").

[10] Off. for Civ. Rights, Dep't of Health & Human Servs., *Frequently Asked Questions: If I am unconscious or not around, can my health care provider still share or discuss my health information with my family, friends, or others involved in my care or payment for my care?*, http://www.hhs.gov/ocr/privacy/hipaa/faq/disclosures_to_friends_and_family/524.html (last visited Apr. 24, 2013).

[11] 45 C.F.R. § 164.501, 164.502(a)(1), 164.506(b-c), 164.508(a)(2), 164.510(a-b).

[12] 45 C.F.R. § 164.512.

[13] *See generally*, Off. for Civ. Rights, Dep't of Health & Human Servs., *Frequently Asked Questions: Who must comply with HIPAA privacy standards?*, http://www.hhs.gov/ocr/privacy/hipaa/faq/covered_entities/190.html (last visited Apr. 24, 2013); Off. for Civ. Rights, Dep't of Health & Human Servs., *Frequently Asked Questions: Does the HIPAA Privacy Rule apply to an elementary or secondary school?*, http://www.hhs.gov/ocr/privacy/hipaa/faq/ferpa_and_hipaa/513.html (last visited Apr. 24, 2013) ("In most cases, the HIPAA Privacy Rule does not apply to an elementary or secondary school because the school either: (1) is not a HIPAA covered entity or (2) is a HIPAA covered entity but maintains health information only on students in records that are by definition "education records" under FERPA and, therefore, is not subject to the HIPAA Privacy Rule.").

[14] 45 C.F.R. § 164.512; John C. Moskop et al., *From Hippocrates to HIPAA: Privacy and Confidentiality in Emergency Medicine – Part I: Conceptual, Moral, and Legal Foundations*, 45 ANNALS OF EMERGENCY MED. 1, 56 (2005).

5. ***Judicial and administrative proceedings***;

6. ***Law enforcement purposes***;

7. ***Decedents*** (e.g. disclosures about the deceased to coroners, medical examiners, funeral directors, etc.);

8. ***Cadaveric organ, eye, or tissue donation***;

9. ***Research*** (e.g. under circumstances authorized by an Institutional Review Board);

10. ***Serious threat to health or safety*** (if necessary to prevent or mitigate a serious and imminent threat to the public or to a specific person, information may be disclosed to any person perceived to be able to prevent or lessen the threat, including caregivers and law enforcement);

11. ***Essential government functions*** (e.g. military purposes); and

12. ***Workers compensation***.

HIPAA's law enforcement exception is particularly detailed, as it provides six circumstances in which protected health information may be disclosed without the individual's authorization:[15]

1. As required by law (including court orders, court-ordered warrants, subpoenas) and administrative requests;

2. To identify or locate a suspect, fugitive, material witness, or missing person;

3. In response to a law enforcement official's request for information about a victim or suspected victim of a crime;

4. To alert law enforcement of a person's death, if the covered entity suspects that criminal activity caused the death;

5. When a covered entity believes that protected health information is evidence of a crime that occurred on its premises; and

6. By a covered health care provider in a medical emergency not occurring on its premises, when necessary to inform law enforcement about the commission and nature of a crime, the location of a crime or crime victims, and the perpetrator of the crime.

Further, there is a sweeping HIPAA exception for national security purposes, which permits the disclosure of protected health information "to authorized federal officials for the

[15] 45 C.F.R. § 164.512(f).

conduct of lawful intelligence, counter-intelligence, and other national security activities authorized by the National Security Act."[16] Similar disclosures are authorized for the "provision of protective services" for the U.S. President, foreign heads of state, and others, including for "the conduct of investigations."[17] This information may then be shared with state and local law enforcement, and because it falls under one of HIPAA's exemptions, there is no requirement that the individual authorize or even receive notice that his or her medical records are being reviewed by law enforcement. In fact, if a person's protected health information is sought under the authority of the Patriot Act,[18] the HIPAA covered entity is prohibited from telling "any other person (other than those persons necessary to produce the tangible things under this section) that the Federal Bureau of Investigation has sought or obtained tangible things."[19]

In short, HIPAA already has ample exceptions for law enforcement and public safety concerns. These specific law enforcement exceptions to HIPAA, along with the broad exception for covered entities if the provider perceives that there is a serious threat to health or safety, provide significant exceptions to privacy protections in the unusual event that an individual poses a serious health or safety threat to self or others. The cumulative impact of all of HIPAA's public interest-related exceptions is to ensure that health care providers can share protected health information when the balance of interests weighs more heavily in favor of the public than the individual's constitutionally and statutorily-protected right to privacy. However, this balance is a delicate one, as too many exceptions to patient privacy will discourage people from seeking treatment, erode the doctor-patient relationship, increase the risk of medical privacy breaches, and ultimately result in negative health outcomes. HIPAA strikes such a balance, to the benefit of individuals and the public.

We welcome the opportunity to discuss HIPAA in more depth, and thank the Subcommittee for its attention to HIPAA's provisions and the larger issue of patient privacy. Please do not hesitate to contact Jennifer Mathis, Bazelon Center for Mental Health Law, at (202) 467-5730 ext. 313, Demelza Baer, American Civil Liberties Union, at (202) 715-0807, or Ari Ne'eman, Autistic Self Advocacy Network, at (202) 596-1056, with any further questions.

Sincerely,

American Civil Liberties Union

Autistic Self Advocacy Network

Bazelon Center for Mental Health Law

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[16] 45 C.F.R. 164.512(k)(2).
[17] 45 C.F.R. § 164.512(k)(3).
[18] USA PATRIOT Act, 50 U.S.C. § 501(a)(1)(2002) (The FBI Director or his designee may get a court order under the Foreign Intelligence Surveillance Act "requiring the production of any tangible things (including books, records, papers, documents, and other items) for an investigation to protect against international terrorism or clandestine intelligence activities, provided that such investigation of a United States person is not conducted solely upon the basis of activities protected by the first amendment to the Constitution.").
[19] 50 U.S.C. § 501(c)(2) & (d).