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Piercing the Privacy Veil: Toward a Saner Balancing of Privacy and Health in Cases of Severe Mental Illness

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Piercing the Privacy Veil: Toward a Saner Balancing of Privacy and Health in Cases of Severe Mental Illness

JORGIO CASTRO*

On November 19, 2013, Virginia state senator and former candidate for governor Robert Creigh Deeds suffered a high-profile attack from his son, who had been diagnosed with schizophrenia, resulting in permanent injuries to himself and his son's self-inflicted death. On June 16, 2015, Senator Deeds addressed Congress to highlight one of the biggest challenges to providing adequate intervention and support for his son—the HIPAA Privacy Rule's restriction on the release of protected health information to family caretakers. Senator Deeds's high-profile story emerged as a national indication of a serious problem: the immense difficulty experienced by families trying to obtain critical information regarding their loved one diagnosed with serious mental illness. While the delivery of adequate mental health treatment is a large and complicated effort governed by many regulatory statutes, advocates have identified in particular the barrier on receiving information from health care providers regarding their loved one's illness—particularly during involuntary psychiatric holds—as one key barrier to effectively assisting in their treatment. Although the Privacy Rule attempts to balance competing principles of respect for autonomy, the best interests of the patient, and efficiency of the system, it has created substantial barriers to effective treatment in this area without actually advancing its purposes. This Note suggests possible fixes for this exigent issue.

* J.D. Candidate, 2015, University of California Hastings College of Law. I would like to thank Professors Robert Schwartz and Lois Weithorn, who have provided tremendous support, assistance, and feedback in the creation of this Note. Thank you to the staff of *Hastings Law Journal* for all of their work on this Note, especially Volume 66 Executive Notes Editor, H. Elliot Hosman, and Volume 67 Executive Notes Editor, Elizabeth Lee. I would also like to thank my parents, extended family, and friends. This Note is dedicated to those suffering from serious mental illness, and the family and friends who love them and are struggling to help.

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INTRODUCTION

The Health Insurance Portability and Accountability Act (“HIPAA”) contains strict privacy provisions that protect individually identifiable health information. In general, the provisions prevent release

of information to anyone other than the patient or the patient's personal representative without explicit consent from the individual patient.¹ Many state privacy laws do the same,² also mandating notice about these information disclosure regulations to an individual being held under an involuntary psychiatric hold.³ HIPAA's default restriction against release of patient information acts as a barrier to family caregivers⁴ receiving information about their loved one during an involuntary psychiatric hold. In many instances this barrier to sharing poses a serious problem to individuals' long-term health and to the family caregivers' involvement in their care.⁵

Family caregivers are often left uninformed of either the details of their family member's diagnosis or symptoms,⁶ as well as the details of treatments available or under consideration.⁷ Further, HIPAA's Privacy Rule ("Privacy Rule") often prevents family caregivers from even knowing if a hospital is involuntarily holding their family member.⁸

1. 45 C.F.R. § 164.502 (2014); *see also* U.S. DEP'T OF HEALTH & HUM. SERVS., OFFICE FOR RIGHTS, SHARING HEALTH INFORMATION WITH FAMILY AND FRIENDS, <http://www.hhs.gov/ocr/privacy/hipaa/understanding/consumers/sharing-family-friends.pdf> (last visited Aug. 5, 2015). Individual psychotherapy notes are even harder on which to receive information. *See* 45 C.F.R. § 164.508 (2014).

2. This Note will not discuss state privacy law in detail. *See infra* note 55.

3. *See, e.g.*, CAL. WELF. & INST. CODE §§ 5150(f)(1), (h)(1) (West 2014) (requiring the provision of information about the basis for the hold, the individual's rights, and the basic contours of the hold); *see also* Patient Self-Determination Act, 42 U.S.C.A. § 1395cc(f)(1)(A)(i) (West 2011) (requiring disclosure of rights and policies of providers that receive Medicaid or Medicare funding). Here, there is a mandated effort to give individual information on which to base subsequent medical decisions, even under circumstances calling into question their ability to make those decisions.

4. "Family caregiver" or "family caretaker" is used throughout the Note to also include close friends and adults who exhibit special care and concern for the patient. Similarly, "family member" or "loved one" will be used to include those close friends and adults who are the subject of that special care and concern. This reflects an inclusive definition of family that has been accepted by many state legislatures and the Uniform Law Commissioners. *See infra* Part III.B.

5. *Tell Your Representative That HIPAA Hurts People with Severe Mental Illness*, TREATMENT ADVOC. CENTER (Apr. 25, 2013), <http://www.treatmentadvocacycenter.org/about-us/our-blog/69-no-state/2299-tell-your-representative-that-hipaa-hurts-people-with-severe-mental-illness>.

6. In many state jurisdictions, some information can be released by the treatment provider under a "duty to warn" if an individual has stated an intention to harm another. *See Tarasoff v. Regents of Univ. of Cal.*, 551 P.2d 334 (Cal. 1976); *see also* 45 C.F.R. § 164.512(j) (2014) (permitting covered entities to release PHI over patient's objection "to avert a serious threat to health or safety"). This Note proposes release of more information to specified caregivers for the long-term treatment of the individual, independent of any threats to those caregivers.

7. *Mother Sues Son for Access to Medical Records*, TREATMENT ADVOC. CENTER (Oct. 2, 2013), <http://www.treatmentadvocacycenter.org/about-us/our-blog/128> ("The Treatment Advocacy Center routinely receives phone calls from patients and family members frustrated that privacy laws prevent them from helping desperately ill loved ones get appropriate treatment and keep them from being aware of safety issues.").

8. Caregivers can still offer information to the health care provider. *See HIPAA at a Glance*, TREATMENT ADVOC. CENTER, <http://www.treatmentadvocacycenter.org/component/content/article/1850> (last visited Aug. 5, 2015); *see also HIPAA Privacy Rule and Sharing Information Related to Mental Health*, U.S. DEPARTMENT HEALTH & HUM. SERVICES, <http://www.hhs.gov/ocr/privacy/hipaa/understanding/special/mhguidance.html> (last visited August 5, 2015) ("HIPAA in no way prevents health care providers

Furthermore, when an individual is involuntarily held⁹ for meeting certain criteria stemming from mental illness,¹⁰ the effects of her mental illness on her ability to make well-considered and wise decisions in her own best interests¹¹ often prevent her from consenting to release of the health information, or even undergoing treatment because of an inability to recognize the existence of the illness.¹² This Note will explore this problem and propose changes to both the Privacy Rule and its implementation in order to more effectively address the challenges faced by patients, families, and American society.¹³

This Note will also explore the problem created by the Privacy Rule's prevention of release of information to an individual's family member when the individual is held on an involuntary psychiatric hold. It will discuss current doctrines and rationales in the context of health care decisionmaking.

Finally, this Note will propose several solutions to the problem. The first proposal calls for instituting a college HIPAA waiver process that designates a family caregiver to receive notice when a family member is

from listening to family members or other caregivers who may have concerns about the health and well-being of the patient . . .”).

9. The term “involuntary psychiatric hold” comes from many state statutes that provide for the hospitalization and monitoring of an individual for a short period of time under certain conditions. *See, e.g.*, CAL. WELF. & INST. CODE § 5150 (West 2014). The purpose of such holds is to “determine whether the person is in such mental condition as to justify the state in depriving him of his personal liberty and *affording him, if it is found needed, benefit of proper care and remedial aid.*” *Hsu v. Mt. Zion Hosp.*, 66 Cal. Rptr. 659, 664 (Ct. App. 1968) (emphasis added).

10. When the term “mental illness” has been used in federal legislation, it traditionally has been interpreted to include all disorders in the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders. *See* Marcia C. Peck & Richard M. Scheffler, *An Analysis of the Definitions of Mental Illness Used in State Parity Laws*, 53 PSYCHIATRIC SERVICES 1089, 1090 (2002).

11. *The Anatomical Basis of Anosognosia (Lack of Awareness of Illness)*, TREATMENT ADVOC. CENTER (May 2013), http://www.treatmentadvocacycenter.org/storage/documents/Research/anosognosia_backgroundunder_may_2013.pdf.

12. Xavier F. Amador & Andrew A. Shiva, *Insight into Schizophrenia: Anosognosia, Competency, and Civil Liberties*, 11 GEO. MASON U. C.R. L.J. 25, 28 (2000) (“Poor insight in schizophrenia bears remarkable similarities to anosognosia in neurological disorders. Patients with schizophrenia who have poor insight, and neurological disorder patients with anosognosia, exhibit the following characteristics: a very severe lack of awareness of their illness, the belief persisting despite conflicting evidence, confabulations to explain the observations that contradict their belief that they are not ill, and a compulsion to prove their self-concept.”).

13. The Author would like to emphasize that mental illnesses, including serious mental illnesses, are more treatable now than ever before. Recovery is possible and has been the subject of major movies and popular culture. *See, e.g.*, Steve Lopez, *Checking in with Nathaniel Ayers*, L.A. TIMES (Oct. 11, 2014), <http://www.latimes.com/local/la-me-1012-lopez-nateupdate-20141011-column.html> (providing update on Nathaniel Ayers, who columnist, Steve Lopez, has known for ten years); THE SOLOIST (DreamWorks Pictures 2009) (detailing the experiences of Nathaniel Ayers, Julliard-trained bassist). *See also* Nicole Mulvaney, ‘A Beautiful Mind’ Mathematician at Princeton University Awarded \$800k Abel Prize, NJ.COM (Mar. 25, 2015 6:05 PM), http://www.nj.com/mercer/index.ssf/2015/03/a_beautiful_mind_princeton_university_mathematicia.html (exploring the life of the late John Nash, Noble Laureate in Economics); A BEAUTIFUL MIND (Universal Pictures 2001). Some accomplish the extraordinary. Many contribute to society. All create meaningful lives.

admitted to an involuntary psychiatric hold.¹⁴ Second, this Note proposes recognizing “family caregivers” to be defined broadly to include individuals not related by blood or marriage as part of the potential treatment team. Finally, this Note suggests recognizing family caregivers as personal representatives within the language of the HIPAA statute, and thus affording them access to the individual’s protected health information (“PHI”).¹⁵

Part I will discuss the current Privacy Rule and its effect on the release of information during involuntary psychiatric holds. Part II will discuss providers’ incentives to withhold information, even when release is permitted under the Privacy Rule. Part III will discuss principles, doctrines, and statutory schemes underlying health care decisionmaking generally, and the decision to release health information specifically. Part IV will discuss possible solutions consistent with those general health care decisionmaking principles.

I. THE PRIVACY RULE IN A NUTSHELL

Congress passed HIPAA in 1996, and the Act’s Privacy Rule took effect in 2003.¹⁶ Congress then made amendments to HIPAA in the American Recovery and Reinvestment Act of 2009,¹⁷ and added the final HIPAA amendments in 2013.¹⁸ The Department of Health and Human Services (“DHHS”) has statutory authority to promulgate regulations under the Privacy Rule¹⁹ and is responsible for enforcing the Privacy Rule.²⁰ In the Standards for Privacy of Individually Identifiable Health Information, DHHS provides:

14. The proposal only affects adults eighteen years and older because before then, adult caretakers such as parents or guardians of an individual generally have access to their health information.

15. 45 C.F.R. § 160.103 (2014).

16. Health Insurance Portability and Accountability Act of 1996, Pub. L. No. 104-191, 110 Stat. 1936 (codified as amended in scattered sections of 26, 29, and 42 U.S.C.).

17. American Recovery and Reinvestment Act of 2009, Pub. L. No. 111-5, 123 Stat. 115 (codified as amended in scattered sections of U.S.C.).

18. Modifications to HIPAA Rules, 78 Fed. Reg. 5566 (Jan. 25, 2013).

19. 45 C.F.R. §§ 160, 164.102–106 & 164.500–534.

20. *HIPAA Enforcement*, U.S. DEP’T. OF HEALTH & HUM. SERVS., <http://www.hhs.gov/ocr/privacy/hipaa/enforcement/index.html> (last visited Aug. 5, 2015).

This regulation has three major purposes: (1) To protect and enhance the rights of consumers by providing them access to their health information and controlling the inappropriate use of that information; (2) to improve the quality of health care in the United States by restoring trust in the health care system among consumers, health care professionals, and the multitude of organizations and individuals committed to the delivery of care; and (3) to improve the efficiency and effectiveness of health care delivery by creating a national framework for health privacy protection that builds on efforts by states, health systems, and individual organizations and individuals.²¹

Expert commentators note that the Privacy Rule establishes “a set of basic national privacy standards and fair information practices that provides all Americans with a basic level of protection and peace of mind that is essential to their full participation in their care” and a “floor of ground rules for health care providers . . . to follow, in order to protect patients and encourage them to seek needed care.”²² Thus, a key rationale underlying the Privacy Rule is that it will encourage individuals to seek health care when they are sick (and know that they have an illness²³) because they will be confident that their private medical information will be kept private. Generally, that is a strong normative argument in favor of the Privacy Rule and its robust protections. The ability of the Privacy Rule to effectuate peace of mind to encourage people to seek care relies upon the individual having a subjective understanding that they have an illness. Without that understanding, there is no motivation to seek treatment, regardless of the Privacy Rule’s existence. People who suffer from serious mental illness,²⁴ but lack understanding of their illness, will not seek treatment.²⁵ This is especially true under an involuntary psychiatric hold, where the individual often

21. Standards for Privacy of Individually Identifiable Health Information, 65 Fed. Reg. 82462, 82463 (Dec. 28, 2000).

22. BARRY FURROW ET AL., HEALTH LAW: CASES, MATERIALS, AND PROBLEMS 268 (2013).

23. One court that defined the “plain and ordinary meaning” of the term “illness” defined it as “any abnormal condition of the body or its components of such a degree that in its natural progression would be expected to be problematic; a deviation from the healthy or normal state affecting the functions or tissues of the body; an inherent defect of the body; or a morbid physical or mental state which deviates from or interrupts the normal structure or function of any part, organ, or system of the body and which is manifested by a characteristic set of symptoms and signs.” *Katskee v. Blue Cross/Blue Shield of Neb.*, 515 N.W.2d 645, 651 (Neb. 1994).

24. This Note adheres to “people-first” language terminology used to describe conditions accurately and not increase stigma against people suffering from such illnesses. See JOHN PARRY & ERIC Y. DROGIN, MENTAL DISABILITY LAW, EVIDENCE AND TESTIMONY: A COMPREHENSIVE REFERENCE MANUAL FOR LAWYERS, JUDGES AND MENTAL DISABILITY PROFESSIONALS 49–53 (A.B.A. 2007); see also Carey Goldberg, *A Phrase to Renounce for 2014: ‘The Mentally Ill’*, WBUR’s COMMONHEALTH (Jan. 3, 2014, 1:57 PM), <http://commonhealth.wbur.org/2014/01/renounce-term-the-mentally-ill> (showing the highly influential Associated Press style guide adopting the position with a “new entry on mental illness [that] says to refer to people ‘diagnosed with schizophrenia instead of schizophrenics’”).

25. Ronald C. Kessler et al., *The Prevalence and Correlates of Untreated Serious Mental Illness*, 36 HUM. SERVICES RES. 987, 1000 (Dec. 2001) (“[T]he majority of untreated people with SMI do not believe that they have emotional problems that require treatment.”).

did not seek out the treatment in the first instance. In these cases, the Privacy Rule does not and cannot achieve that purpose of encouraging people to seek health care. As a countervailing consideration, the Privacy Rule also attempts to balance public responsibility with privacy protections.²⁶ This Note takes the position that in the area of involuntary psychiatric holds, providers have shifted the balance too far away from public responsibility by preventing release of information when a family member is on an involuntary hold.

A. THE PRIVACY RULE CURRENTLY ALLOWS HEALTH CARE PROVIDERS TO DENY RELEASE OF INFORMATION TO FAMILY CARETAKERS WHEN A FAMILY MEMBER IS ON A PSYCHIATRIC HOLD

HIPAA and the Privacy Rule create problems in the context of mental illness because they were not “written with mental illness in mind.”²⁷ This oversight results in serious problems when HIPAA inevitably impacts the rights and treatment of individuals suffering from mental illness.

Even in the face of the long-standing stigma surrounding mental illness, the national conversation on mental health, illness, and treatment continues to expand.²⁸ Advocates have coalesced and organizations have formed in order to fight against and change the existing societal stigmas against mental illness.²⁹ President Barack Obama remarked during his 2015 State of the Union Address, “we’re a people who value the dignity and worth of every citizen . . . [including] Americans with mental illness or physical disability. Everybody matters.”³⁰ The national conversation reflects a greater awareness of mental illness, as serious mental illnesses

26. FURROW ET AL., *supra* note 22, at 278; *see also* HIPAA Privacy Rule and Sharing Information, *supra* note 8, at 1 (“At the same time, the Privacy Rule recognizes circumstances arise where health information may need to be shared to ensure the patient receives the best treatment and for other important purposes, such as for the health and safety of the patient or others.”).

27. Jenny Gold, *Privacy Law Frustrates Parents of Mentally Ill Adult Children*, NPR (June 4, 2014, 4:41 PM), <http://www.npr.org/blogs/health/2014/06/04/318765929/privacy-law-frustrates-parents-of-mentally-ill-adult-children>.

28. *President Obama Opens White House Mental Health Conference*, C-SPAN (June 3, 2013), <http://www.c-spanvideo.org/program/313109-1>; *Untreated Mental Illness an Imminent Danger?*, CBS NEWS (Sept. 29, 2013, 7:00 PM), <http://www.cbsnews.com/videos/untreated-mental-illness-an-imminent-danger>; *see also* Nicholas Kristof, *First Up, Mental Illness. Next Topic Is Up to You*, N.Y. TIMES (Jan. 4, 2004), <http://www.nytimes.com/2014/01/05/opinion/sunday/kristof-first-up-mental-illness-next-topic-is-up-to-you.html>.

29. *See* BRING CHANGE 2 MIND, www.bringchange2mind.org (last visited Aug. 5, 2015); *Fight Stigma: Become a StigmaBuster!*, NAT'L ALLIANCE ON MENTAL ILLNESS, http://www.nami.org/Content/NavigationMenu/Take_Action/Fight_Stigma/Fight_Stigma_StigmaBusters.htm (last visited Aug. 5, 2015); PROJECT 375, <http://project375.org> (last visited Aug. 5, 2015); *Mental Health Program*, CARTER CENTER, http://www.cartercenter.org/health/mental_health/index.html (last visited Aug. 5, 2015).

30. President Barack Obama, State of the Union Address (Jan. 20, 2015), *transcript available at* <http://www.whitehouse.gov/the-press-office/2015/01/20/remarks-president-state-union-address-january-20-2015>.

affect a large portion of the population—one in seventeen people.³¹ Some of these illnesses, including major depression, bipolar disorder, schizophrenia, and obsessive-compulsive disorder, are incredibly debilitating and dangerous, and in some instances, lead to suicide and higher rates of morbidity.³² As attention and funding are brought to bear on services for mental illness, the involvement of the family members and loved ones who provide caregiving and support remains an integral aspect of the treatment process for people with mental illness.³³ One critical component of involving family caregivers in an individual's treatment is the information regarding the patient's diagnosis, prognosis, and treatment plans.³⁴ The Privacy Rule's current "authorization"

31. *Serious Mental Illness (SMI) Among U.S. Adults*, NAT'L INST. MENTAL HEALTH, <http://www.nimh.nih.gov/health/statistics/prevalence/serious-mental-illness-smi-among-us-adults.shtml> (estimating 9.6 million Americans, or 4.1% of population, have serious mental illness). The statistics also acknowledge that people with serious mental illness are disproportionately less likely to answer the survey, suggesting the prevalence is higher. *Id.* See also Press Release, World Health Org., *Mental Disorders Affect One in Four People* (Oct. 2001), available at http://www.who.int/whr/2001/media_centre/press_release/en/ (finding 450 million people worldwide suffer from a mental disorder).

32. See *General Mental Illness*, BRAIN & BEHAV. RES. FOUND., <https://bbrfoundation.org/mental-illness-1> (noting the four diagnoses are amongst ten "leading causes of disability identified and tracked in the United States and other developed countries"); Elizabeth Resinger et al., *Mortality in Mental Disorders and Global Disease Burden Implication: A Systemic Review and Meta-Analysis*, 72 JAMA PSYCHIATRY 334 (Feb. 11, 2015), <http://archpsyc.jamanetwork.com/article.aspx?articleid=2110027> (finding "median years of potential life lost was 10 years" and concluding "estimates suggest that mental disorders rank among the most substantial causes of death worldwide"); *Depression Facts and Statistics*, DEPRESSION PERCEPTION, <http://www.depressionperception.com/depression/depression-facts-and-statistics.html> (last visited Aug. 5, 2015).

33. Ian R.H. Falloon, *Family Interventions for Mental Disorders: Efficacy and Effectiveness*, WORLD PSYCHIATRY (Feb. 2003), <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1525058> ("There is sufficient scientific evidence to conclude that strategies that enhance the caregiving capacity of family members and other people involved in the day to day care for people with mental disorders have a clinically significant impact on the course of major mental disorders."). A second interwoven rationale allows PHI disclosure to stem from family members' desire to have information regarding where the individual is, when they may not know, and to promote reunification. See, e.g., *Accusations of Patient Dumping*, ABC NEWS (May 2, 2013), <http://abcnews.go.com/WNT/video/accusations-patient-dumping-19096538> (showing James Brown suffering from severe mental illness, discharged from state hospital, and sent out of state). Later, social workers helped contact Brown's daughter, which led to reunification. See Cynthia Hubert, *Mentally Ill Man 'Dumped' by Nevada Has Happy Reunion with Daughter*, SACRAMENTO BEE (Apr. 12, 2013), <http://www.sacbee.com/2013/04/12/5336162/mentally-ill-man-dumped-by-nevada.html> (describing his daughter's lack of knowledge of Brown's whereabouts, their reunification, and subsequent treatment plans and accommodations). Other stories drag on longer or do not end so happily. See Ryan Lavis, *Mental Illness and Missing Adults: Experts and Family Members Say the Law Hinders Search Efforts for Loved Ones*, SILIVE.COM (May 4, 2014, 8:16 PM), http://www.silive.com/news/index.ssf/2014/05/mental_illness_and_missing_adu.html ("When a family is trying to look for them, they can call every hospital in the area, but they can't even tell them if their family member is there—it's a big problem.").

34. See, e.g., Anthony F. Lehman et al., *At Issue: Translating Research into Practice: The Schizophrenia Patient Outcomes Research Team (PORT) Treatment Recommendations*, 24 SCHIZOPHRENIA BULLETIN 1, 8 (1998) ("Randomized clinical trials have repeatedly demonstrated that family interventions that provide some combination of illness education, support, problem-solving training, and crisis intervention, in combination with appropriate pharmacotherapy, reduce 1-year relapse rates from a 40 to 53 percent range to a 2 to 23 percent range.").

requirement stands as one significant barrier to the critical component of caregiver involvement.

The Privacy Rule currently requires “authorization” before a “covered entity” can release medical information about a particular patient to another party.³⁵ A “covered entity” is any health care plan or provider that transmits health information in electronic form.³⁶ In the case of individuals suffering from a severe psychotic episode³⁷ or other event that necessitates short-term involuntary commitment, the Privacy Rule’s prerelease authorization requirement is problematic because it presupposes the capacity to make such an authorization that many might lack during this time. Although there is one such exception for sharing information under the Privacy Rule, it is complicated, left to the discretion of the health care provider, and importantly, rarely actually used in practice.³⁸

This Note discusses how to fix the exception for sharing information in order to better serve the interests of the patient. One possible way to circumvent the exception’s current barriers is to categorize the disclosure of the patient’s treatment under involuntary psychiatric hold orders to a known family caregiver as a form of “treatment” under HIPAA.³⁹ Thus, explicit authorization during an illness would no longer be required in certain circumstances, and family caregivers’ role in the long-term treatment of their loved ones would be formally recognized in the Privacy Rule.⁴⁰ Another solution this Note explores is to amend the Privacy Rule to include designated family caregivers as “personal representatives,”⁴¹ who, under HIPAA, would be entitled to receive the

35. 45 C.F.R. § 164.502 (2014).

36. *Id.*

37. See *Psychosis*, MEDLINEPLUS MEDICAL ENCYCLOPEDIA, <http://www.nlm.nih.gov/medlineplus/ency/article/001553.htm> (defining psychosis as a “los[s] of contact with reality,” which usually includes, “[having] false beliefs about what is taking place or who one is (delusions)” and “see[ing] or hear[ing] things that aren’t there (hallucinations)” and disorganized thought and speech).

38. Tim Murphy, *The Helping Families in Mental Health Crisis Act*, <http://murphy.house.gov/uploads/Summary.pdf> (finding lack of information sharing “because of complicated federal rules on communicating with immediate family members and caregivers”). Congressman Murphy’s bill also includes important policy changes to increase inpatient psychiatric beds, to increase rural and underserved area access to psychologists and psychiatrists, to ensure NIMH money and federal grants are directed towards evidence-based care, to guarantee Medicare and Medicaid coverage for psychiatric drugs, to support NIMH research, and to support reauthorization of mental health courts and training for law enforcement officers that interact with people going through acute psychiatric crisis. *Id.*; see also *HIPAA at a Glance*, *supra* note 8.

39. The Privacy Rule defines treatment as “the provision, coordination, or management of health care and related services by one or more health care providers, including the coordination or management of health care by a health care provider with a third party.” 45 C.F.R. § 164.501 (2014). The Privacy Rule permits use or disclosure of PHI for a covered entity’s own treatment purposes, or the treatment activities of a health care provider. 45 C.F.R. § 164.506(c)(1)–(2) (2014).

40. See *infra* Part IV.B.

41. 45 C.F.R. § 164.502(g)(1) (2014).

patient's individually identifiable health information on her behalf.⁴² Yet another possible approach is to institute a "psychiatric advance directive"⁴³ during college and post-secondary education enrollment—when many mental illnesses first emerge.⁴⁴ Such a directive would specifically authorize information sharing, particularly during a future acute psychiatric crisis.⁴⁵ These implementations would provide clearer, more effective guidance for when information should be released, and would more definitively advance individual and family interests.

B. THE PRIVACY RULE CURRENTLY MANDATES "INCAPACITY" TO ALLOW DISCLOSURE OF PROTECTED HEALTH INFORMATION TO FAMILY CAREGIVERS

A slight exception to the stringent Privacy Rule currently exists for limited emergency circumstances. Where a patient is considered "not present" due to "incapacity or an emergency situation, the Privacy Rule permits disclosures that the provider considers to be in the best interest of the patient, but limits the information to that which is directly relevant to the person's involvement in the patient's health care."⁴⁶ With this exception, the Privacy Rule contemplates the situation where an individual is involuntarily held, and allows for flexibility "in the best interests" of the patient.⁴⁷ This shows that the Privacy Rule's intent is not to completely prevent the flow of information from the provider to family caregivers about an individual's health during such a critical period,⁴⁸ but rather to limit release to cases where the physician concludes in her professional judgment that it is in the patient's best interest.

However, the current exception has two clear shortcomings. First, it is unclear and obscure, providing no guidance as to the exception's policy rationale for providers.⁴⁹ Second, the release of information is only

42. See *infra* Part IV.C.

43. See *infra* Part III.C.

44. Press Release, Nat'l Inst. Mental Health, Mental Illness Exacts Heavy Toll, Beginning in Youth (June 6, 2005), available at <http://www.nimh.nih.gov/news/science-news/2005/mental-illness-exacts-heavy-toll-beginning-in-youth.shtml> ("Half of all lifetime cases begin by age 14; three quarters have begun by age 24. Thus, mental disorders are really the chronic diseases of the young.").

45. See *infra* Part IV.A.

46. Richard C. Boldt, *Adolescent Decisionmaking: Legal Issues with Respect to Treatment for Substance Misuse and Mental Illness*, 15 J. HEALTH CARE L. & POL'Y 75, 113 n.265 (2012); see also 45 C.F.R. § 164.510(b)(3) (2014); *HIPAA Privacy Rule and Sharing Information*, *supra* note 8.

47. This Note will discuss the "best interests" doctrine. See *infra* Part III.

48. U.S. DEP'T. OF HEALTH & HUM. SERVS., SUMMARY OF THE HIPAA PRIVACY RULE (2003), <http://www.hhs.gov/ocr/privacy/hipaa/understanding/summary/privacysummary.pdf> (stating the main purpose of the HIPAA Privacy Rule is to define and limit when the PHI of an individual may be used or disclosed by covered entities).

49. *Adolescent Decisionmaking*, *supra* note 46; see also FURROW ET AL., *supra* note 22, at 277 ("Nurses can speak over the phone with a patient or family member about the patient's condition.").

permitted, not required.⁵⁰ Because this release exception is unclear and only permissive, health care providers do not, as a matter of hospital policy, release PHI to the individual's family without express written consent.⁵¹ A key question is: Why?

II. HEALTH CARE PROVIDERS HAVE INCENTIVES TO NOT PERMIT DISCLOSURE, EVEN WHEN THEY CAN

Health care providers might not permit disclosure of protected health information for various reasons including liability, ambiguity of liability, and financial and administrative costs. A provider may likely enact a blanket policy of nondisclosure to avoid possible penalization by the Office of Civil Rights of the DHHS ("OCR").⁵² But the OCR does not explicitly preclude a hospital representative from speaking over the phone with a family member about the patient's condition, and the release of such information is authorized in circumstances where the physician deems it in the best interest of the patient.⁵³ By adopting a nondisclosure policy, providers are acting with an overabundance of caution to the detriment of the patient. This excessive caution is unwarranted given HIPAA's history of not penalizing covered entities who violate the Privacy Rule.⁵⁴ Alternatively, the health care provider may also be attempting to avoid violation of state confidentiality laws.⁵⁵

50. OFFICE FOR CIVIL RIGHTS, A HEALTH CARE PROVIDER'S GUIDE TO THE HIPAA PRIVACY RULE: COMMUNICATING WITH A PATIENT'S FAMILY, FRIENDS, OR OTHERS INVOLVED IN THE PATIENT'S CARE 2, http://www.hhs.gov/ocr/privacy/hipaa/understanding/coveredentities/provider_ffg.pdf (last visited Aug. 5, 2015); see also *HIPAA Privacy Rule and Sharing Information*, *supra* note 8, at n.1 ("The Privacy Rule permits, but does not require, providers to disclose information in these situations. Providers who are subject to more stringent privacy standards under other laws, such as certain state confidentiality laws or 42 C.F.R. Part 2, would need to consider whether there is a similar disclosure permission under those laws that would apply in the circumstances.").

51. *How HIPAA Prevents Seriously Mentally Ill From Getting Good Care and What to Do About It*, MENTAL ILLNESS POL'Y ORG., http://mentalillnesspolicy.org/national-studies/HIPAA_handcuffs.pdf ("covered entities default to nondisclosure"); see also Pete Earley, *HIPAA: Does it Keep Key Information From Family Members*, PETE EARLEY BLOG (May 17, 2013), <http://www.petearley.com/2013/05/17/hipaa-does-it-keep-key-information-from-family-members/> (detailing one family's experience being repeatedly denied any information about their son on the basis of HIPAA, even at one point with written consent from their son).

52. FURROW ET AL., *supra* note 22, at 280–81.

53. See *HIPAA Privacy Rule and Sharing Information*, *supra* note 8.

54. *Does HIPAA Help or Hinder Patient Care And Public Safety?: Hearing Before the Subcomm. on Oversight and Investigations of the Comm. on Energy and Commerce H.R.*, 113th Cong. 33 (2013) (statement of Leon Rodriguez, Director, Office of Civil Rights, Department of Health and Human Services) ("We have received 80,000 complaints since we began enforcing. Only 12 of them have resulted in monetary penalties.").

55. See *HIPAA Privacy Rule and Sharing Information*, *supra* note 8. The Privacy Rule only preempts state confidentiality laws that are directly contrary to it. *How Do Other Privacy Protections Interact with the Privacy Rule?*, U.S. DEP'T OF HEALTH & HUM. SERVS., http://privacyruleandresearch.nih.gov/pr_05.asp (last updated Feb. 2, 2007). To the extent state privacy laws may more stringently prohibit disclosure, this Note advises that states revise their privacy law consistent with this Note's suggestions for HIPAA.

Whatever the statutory concern, it appears that many health care providers have enacted a “prophylactic” policy⁵⁶ against releasing an individual’s mental health information to family caretakers.⁵⁷

Another possible rationale driving health care providers’ blanket nondisclosure policies is their misinterpretation that HIPAA prevents the dissemination of such information without consent in all circumstances.⁵⁸ In fact, OCR had to issue an open letter to the nation’s health care providers on this point, clarifying that HIPAA’s “Privacy Rule does not prevent [their] ability to disclose necessary information about a patient to law enforcement, family members of the patient, or other persons, when [they] believe the patient presents a serious danger to himself or other people.”⁵⁹ Furthermore, OCR clarified that the Privacy Rule offers the provider protection in her dissemination of the patient’s information.⁶⁰ The Privacy Rule establishes that “the provider is presumed to have had a good faith belief when his or her belief is based upon the provider’s actual knowledge . . . or in reliance on a credible representation by a person with apparent knowledge or authority”⁶¹ OCR’s letter referencing these provisions exemplifies the widespread “misunderstanding” of the application of the Privacy Rule⁶² and highlights the primacy that federal privacy law takes, superseding state privacy law when HIPAA is more restrictive than the state law.⁶³ While OCR’s statement suggests that DHHS recognizes the misunderstanding about the nature of HIPAA, this statement solely seeks to clarify *Tarasoff*-like “duty to warn” requirements and protection for health care providers’ disclosures that apply only in limited cases— when there is a

56. The Supreme Court has used the term “prophylactic” to describe cautious measures used to insure other rights are protected, such as the *Miranda* doctrine’s prophylactic protection of the Fifth Amendment right against self-incrimination. See *New York v. Quarles*, 467 U.S. 649, 654 (1984). As this Part and Note points out, however, such prophylaxis is inconsistent with the Privacy Rule itself.

57. See *How HIPAA Prevents*, *supra* note 51 (“[C]overed entities default to nondisclosure”).

58. *Id.* (suggesting this is sometimes done “out of ignorance of the law”).

59. Letter from Leon Rodriguez, Director, Office for Civil Rights, U.S. Dep’t of Health & Hum. Servs., to Our Nation’s Health Care Providers (Jan. 15, 2013), available at <http://www.hhs.gov/ocr/office/lettertonationhcp.pdf>.

60. *Id.*

61. *Id.* See 45 C.F.R. § 164.512(j) (2014).

62. See *HIPAA Privacy Rule and Sharing Information*, *supra* note 8, at 6 (reiterating that the “Privacy Rule permits a health care provider to disclose necessary information about a patient to law enforcement, family members of the patient, or other persons, when the provider believes the patient presents a serious and imminent threat to self or others”). OCR also reiterated the exception for disclosure to family caregivers in light of the Ebola outbreak and other events. See also *Bulletin: HIPAA Privacy in Emergency Situations*, U.S. DEP’T OF HEALTH & HUM. SERVS., (Nov. 2014), <http://www.hhs.gov/ocr/privacy/hipaa/understanding/special/emergency/emergencysituations.pdf>.

63. *HIPAA Privacy Rule and Sharing Information*, *supra* note 8, at 9 (“[M]ost states have laws and/or court decisions which address, and in many instances require, disclosure of patient information to prevent or lessen the risk of harm.”).

serious danger to other persons.⁶⁴ Such a statement only clarifies existing “duty to warn” obligations and does not clarify or highlight the family caregiver exception.

This OCR message also exemplifies another probable reason for the “prophylactic” policy: the confusion that many providers experience about what and when they can share with certain people without the express consent of the patient.⁶⁵ Often, when an actor (here, the health care provider) is unclear about where the law draws the line, she will generally stay far away from the line so as to avoid violating the law and incurring penalties.⁶⁶ To a certain extent, that decision may reflect astute advice from the provider’s legal counsel in an attempt to protect the provider in the face of ambiguous liability. While in some contexts ambiguity may create desirable deterrence from action, in this area, it is in the American public’s best interest for health care providers to both comply with the law and provide the highest quality of care possible. It is essential then that the lawmakers clarify the law in this area. In response to the lack of understanding by health care providers of the Privacy Rule’s treatment of PHI disclosure for family caretakers in this context, DHHS recently released further guidance aimed at clarifying when it is appropriate for a health care provider to share the PHI of a patient who is being treated for a mental health condition.⁶⁷ The guidance directly clarifies, again, that the provider can, if the individual currently lacks capacity, share information with the family member without the patient’s consent if the provider believes it is in the best interest of the patient.⁶⁸

64. See *supra* note 6.

65. See, e.g., Chris Vanderveen, *Family’s Tragedy Could Shed Light on Privacy Laws*, 9NEWS (Feb. 9, 2015), <http://ux.9news.com/longform/news/investigations/2015/02/09/ari-liggett-hipaa/23136843> (quoting sister of man who killed mother stating that the “doctor testified at trial that, because of Ari’s rights and because of HIPAA laws, she was legally obligated to ignore my mom’s phone calls”); see also *Privacy Law Frustrates Parents*, *supra* note 27 (“[P]roblems include plain misunderstanding about what the law requires and allows.”).

66. *HIPAA: What’s Smoke, What’s Fire?—Personally Speaking*, TREATMENT ADVOC. CENTER (Apr. 26, 2013), <http://www.treatmentadvocacycenter.org/about-us/our-blog/69-no-state/2300> (“[W]itnesses all agreed that medical providers typically want to talk to family members but don’t because they feel their lips are sealed by Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule and fear punishment.”); *Privacy Law Frustrates Parents*, *supra* note 27 (suggesting providers “are afraid of being sued”).

67. See *HIPAA Privacy Rule and Sharing Information*, *supra* note 8.

68. The relevant portion reads in part:

If, for example, the provider believes the patient cannot meaningfully agree or object to the sharing of the patient’s information with family, friends, or other persons involved in their care due to her current mental state, the provider is allowed to discuss the patient’s condition or treatment with a family member, if the provider believes it would be in the patient’s best interests. In making this determination about the patient’s best interests, the provider should take into account the patient’s prior expressed preferences regarding disclosures of their information, if any, as well as the circumstances of the current situation.

Id.

A separate interest that the current health care provider default of nondisclosure serves in this case is the patient's privacy interest. While important, that interest is not absolute and should be balanced with the need for coordinated treatment while a patient experiences a severe illness. This privacy interest is still preserved by the fact that the proposed disclosure of the information will be limited only to family caregivers. There is, generally speaking, less of a privacy intrusion in disclosure to family caregivers than disclosure to say, one's employer,⁶⁹ because the "family unit" necessarily includes relationships of trust that very often do not exist in other circumstances.⁷⁰

Yet another interest at work here is that of saving the provider time and money that often comes at the expense of the long-term health and well-being of the patient.⁷¹ For the provider, more contact with more people results in increased paperwork and staff time. Providers would have to either pass such extra costs through their existing financing structure, making the providers' services less attractive to their purchasers, or "eat" the cost from existing budgets. The prophylaxis also arguably serves the providers' related interests in administrative convenience. It takes up less time and energy from busy hospital staff if they do not have to deal with families and caregivers over the phone or in person when policy or law does not require it.⁷² That rationale, again, puts provider interests in "avoiding hassle" above the best interests of the patient.

Despite attempts by OCR to clarify the HIPAA information sharing provision, the permissive nature of the provision giving providers the ability to withhold information stands as an obstacle to serving the best interests of the patient, and inhibits its uniform application by health care providers across the nation. Health care providers still have a big incentive to not "go through all the hassle" of providing as much information as may be permitted by law, even if communication with the family caregiver is in the best interests of the patient's long-term treatment. The fear and uncertainty of civil penalties, administrative costs associated with the increased transactional costs of disseminating information, and general institutional inertia⁷³ all stand as formidable

69. There may be circumstances when such trust does not exist between certain traditional family members. See *infra* Part IV.D.2. This Note uses "family caregiver" and "family caretaker" to describe individuals who exhibit special care and concern for one another and not solely individuals related by blood or law.

70. Again, "family unit" here is more inclusively defined to include close friends and adults that the individual has to chosen to include as "family" in their life.

71. *How HIPAA Prevents Seriously Mentally Ill*, *supra* note 51 ("[I]t serves the purposes of the individual [health care provider] or organization").

72. *Privacy Law Frustrates Parents*, *supra* note 27 ("[P]roviders may be 'hiding behind HIPAA,' so that they don't have to deal with families . . .").

73. "Institutions tend to be sticky—once in place and accepted, they can limit policy change and future choices." *Overcoming Behavioral and Institutional Inertia*, in *WORLD DEV. REP.* 321 (2010),

barriers to the implementation of a policy of standard dissemination of PHI on an involuntary psychiatric hold to family caretakers. Despite OCR's clarifications, a solution that incorporates a required disclosure is still needed to promote compliance by the nation's health care providers.

III. COMPETENCY, DECISIONAL CAPACITY, AND THE DECISION TO RELEASE INFORMATION

When evaluating the decision to release medical information, it is important to first understand the legal framework of how individual patients generally make health care decisions. This Part examines the legal principles that guide who has decisionmaking authority for patients' health care, and how they exercise that authority.

According to long-established common law principles, an individual's competency to make medical decisions is presumed.⁷⁴ State statutory law has widely incorporated and codified this common law principle, presuming that people are competent to make medical decisions, including the decision to release medical information.⁷⁵

The legal concept of decisional capacity, or the ability to make decisions with regard to medical care, has been the subject of considerable and long-standing debate.⁷⁶ The current understanding of decisional capacity examines whether an individual has: "(1) possession of a set of values and goals, (2) the ability to communicate and understand information, and (3) the ability to reason and deliberate about one's choices."⁷⁷ Physicians will often make assessments by asking the patient to make a choice regarding treatment, encouraging the patient to repeat information about the medical condition and treatment, describe their views of the treatment and likely outcomes, and compare

available at <http://siteresources.worldbank.org/INTWDRS/Resources/477365-1327504426766/8389626-1327510418796/Chapter-8.pdf>.

74. *Grannum v. Berard*, 422 P.2d 812, 814 (Wash. 1967) ("It is well settled that the law will presume sanity rather than insanity, competency rather than incompetency . . .").

75. UNIFORM HEALTH-CARE DECISIONS ACT § 11 (1993) (consolidating various state laws related to health care decisionmaking).

76. FURROW ET AL., *supra* note 22, at 1579 ("Courts have been much more likely to finesse the issue out of the law and back into medicine . . . Ironically, medical textbooks point out that the standard for capacity is a legal, not a medical one."); *see also* Robert Miller, *The Continuum of Coercion: Constitutional and Clinical Considerations in the Treatment of Mentally Disordered Persons*, 74 DENV. U. L. REV. 1169, 1198 ("Mental health and legal professionals have often differed in their interpretations of the capacity issue.").

77. PRESIDENT'S COMM'N FOR THE STUDY OF ETHICAL PROBLEMS IN MED. & BIOMEDICAL & BEHAVIORAL RESEARCH, I MAKING HEALTH CARE DECISIONS: A REPORT ON THE ETHICAL AND LEGAL IMPLICATIONS OF INFORMED CONSENT IN THE PATIENT-PRACTITIONER RELATIONSHIP 57-60 (1982). Dr. Paul Appelbaum alternatively describes the legal standard as generally embodying four criteria: "[A]bilit[y] to communicate a choice, to understand the relevant information, to appreciate the medical consequences of the situation, and to reason about treatment choices." Paul S. Appelbaum, *Assessment of Patients' Competence to Consent to Treatment*, 357 NEW ENG. J. MED. 1834, 1835 (2007).

treatment options and consequences to offer reasons for their selection.⁷⁸ In an early and influential article, the authors, Loren Roth, Alan Meisel, and Charles Lidz analyzed various tests for competency and concluded that testing competency to consent to treatment (a previous incarnation to decisional capacity) operated as a sort of “sliding scale” in practice.⁷⁹ Under this sliding scale, if the benefit of treatment was likely to far outweigh the risks, there was a low standard of competency when the patient consented, and a high standard for competency when the patient refused—and vice versa.⁸⁰ In more recent scholarship, Dr. Paul Appelbaum highlights that the “stringency of the test applied varies directly with the seriousness of the likely consequences of patients’ decisions,” a continuation of the sliding scale approach in practice.⁸¹ Arguably, the principle of benevolence and the doctrine of best interests underlie the sliding-scale nature of the application of the competency test.⁸² In other words, when a patient made decisions that were objectively “rational” and comported with what the physician thought was the best decision given the medical circumstances, there was more of a presumption of competency, and thus, a greater incidence of finding competency.⁸³ When decisions were objectively seen as wholly “irrational” given the medical circumstances, the test for competency slid to a higher standard.⁸⁴ To a certain extent, the physician was then more likely to find the individual “incompetent” to make the decision because her decision was not objectively in her best interests.

For individuals involuntarily hospitalized because of an active psychosis or other condition that necessitated their psychiatric hold, all three decisional capacity factors weigh against recognizing that they possess decisional capacity to withhold release of information to a caregiver. When the individual is in the grips of acute psychosis and, for example, under a delusion that she is the Queen of England, making decisions for the good of her subjects, the values and goals she possesses

78. Appelbaum, *supra* note 77, at 1836 tbl. 1.

79. Loren H. Roth et al., *Tests of Competency to Consent to Treatment*, 134 AM. J. PSYCHIATRY 279, 280 (1977); see also Paul S. Appelbaum & Thomas Grisso, *Mental Illness and Competence to Consent to Treatment*, 19 LAW & HUM. BEHAV. 105, 108 (1995) (“[D]epending on the facts of a case and precedent in that jurisdiction, court decisions might be based on one standard or some combination of standards.”).

80. See Roth et al., *supra* note 79.

81. Appelbaum, *supra* note 77, at 1836.

82. See *infra* Part III.A.

83. Roth et al., *supra* note 80, at 281.

84. See James F. Drane, *Competency to Give an Informed Consent: A Model for Making Clinical Assessments*, 252 JAMA 925, 925 (1984) (“Rather than selecting a single standard of competency, a sliding scale is suggested that requires an increasingly more stringent standard as the consequences of the patient’s decision embody more risk.”).

cannot reasonably be described as her own.⁸⁵ Someone suffering from an acute episode of schizophrenia, and speaking in disorganized jumbles of sentences about persecution from everyone working with the government (and with no credible evidence to support such conclusions), cannot reasonably be said to “understand information” or “be able to reason and deliberate.”⁸⁶ An individual suffering through a psychotic manic episode, rapidly cycling through thoughts that are disjointed and grandiose, cannot plausibly be described as able to “reason and deliberate” about her choices.⁸⁷

Indeed, the acute and drastic flare-up that brings an individual into an involuntary hold often happens because the individual’s underlying illness has progressed to a point where her capacity faculties are greatly diminished. When someone meets the criteria for an involuntary hold, there is strong evidence that she does not have the capacity at that point to make decisions regarding treatment⁸⁸ or regarding the release of PHI to a family caretaker as part of that treatment. The state statutes that authorize involuntary holds have at their core the principle that at that time the individual lacks the capacity to make the decision to be taken in for evaluation. Therefore, another legally designated actor makes the determination for the individual, regardless of whether the individual wants the decision to be made; the hold is *involuntary*. Psychosis can last for varying periods, and might abate shortly after an individual is placed on an involuntary hold. However, even after an initial acute psychosis dissipates, many individuals with certain common psychiatric illnesses will continue to suffer from a lack of insight into their illness, a condition known as “anosognosia,”⁸⁹ which will continue to impair two decisional

85. JANET L. DAVIES & ELLEN H. JANOSIK, *MENTAL HEALTH AND PSYCHIATRIC NURSING: A CARING APPROACH* 760 (1991).

86. Such psychotic breaks can also be the result of substance abuse. Many times the presentation of symptoms overlaps so that accurate diagnosis takes some time. See Carol L.M. Caton et al., *Differences Between Early-Phase Primary Psychotic Disorders With Concurrent Substance Use and Substance-Induced Psychoses*, *JAMA PSYCHIATRY* (Feb. 1, 2005), <http://archpsyc.jamanetwork.com/article.aspx?articleid=208288>. Although the two causes may be distinct, the practical effect of their symptoms should apply equally for the decisional capacity analysis.

87. See David DiSalvo, *What Really is a Psychotic Break with Reality?*, *FORBES* (Aug. 10, 2013), <http://www.forbes.com/sites/daviddisalvo/2012/08/10/what-really-is-a-psychotic-break-with-reality/> (“[P]sychotic break with reality’ means losing contact with reality, such as hearing, seeing, tasting, smelling, or feeling something that has no external correlate (i.e., hallucinations) or believing something to be true that is false, fixed, and fantastic (i.e., a delusion) or being unable to sequence one’s thoughts or control a flight of ideas that becomes increasingly tangential (i.e., thought disordered), or emotions wildly inconsistent with external reality (such as catatonia, the wild flights of someone in a manic episode, or a complete absence of affect).”).

88. In California, an involuntary psychiatric hold by itself does not rebut the presumption of competency to make treatment decisions. See CAL. WELF. & INST. CODE §§ 5326.5(d), 5331 (West 2015); *Riese v. St. Mary’s Hosp. & Med. Ctr.*, 271 Cal. Rptr. 199, 208 (Ct. App. 1987).

89. Anosognosia is commonly defined as “lack of insight” or not seeing what ails you. *Anosognosia (Lack of Insight) Fact Sheet*, NAMI, http://www2.nami.org/Content/NavigationMenu/Mental_Illnesses/Schizophrenia/Anosognosia_Fact_Sheet.htm (last visited Aug. 5, 2015). Anosognosia

capacity factors: the ability to communicate and understand information, and the ability to reason and deliberate about one's choices.

The discussion of decisional capacity centers around the question of whether the individual patient has the capacity to make a health care treatment decision. As this Note argues, the release of an individual's medical information during an involuntary psychiatric hold should be liberalized to include informal family caregivers, under the rationale that such a release is part of the individual's treatment. Thus, withholding or disseminating information can be seen as a treatment decision, which should not be left in the hands of an individual who is incapacitated at that time. The next Part discusses how vesting this decision completely in the hands of the incapacitated individual undermines the doctrine of best interests and does not comport with the actual spirit of the principle of autonomy.

A. THE DOCTRINAL UNDERPINNINGS OF HEALTH CARE DECISIONMAKING

The idea underlying the Privacy Rule and compassionate care for an incapacitated individual is the doctrine of best interests.⁹⁰ Under the doctrine of best interests, a surrogate decisionmaker is required to make decisions that best promote the incapacitated individual's welfare.⁹¹ Interestingly enough, the doctrine of best interests initially increased the autonomy of incapacitated individuals during a time when incompetent or incapacitated persons were viewed as property of their guardians.⁹² Thus, the foundation of the doctrine of best interests contains an element of increased autonomy.

Today, the doctrine of best interests and its underlying principle of beneficence often stand counterpoised to the doctrine of "substituted judgment," which seeks to uphold the principle of autonomy.⁹³ The

also commonly occurs in patients with Alzheimer's disease and dementia. *Id.* Anosognosia is distinct from psychological denial, and is regarded as "a core feature of the neurobiology of these conditions." *Id.*; see also Laura Flashman et al., *Specific Frontal Lobe Subregions Correlated with Unawareness of Illness in Schizophrenia*, 13 J. NEUROPSYCHIATRY CLINICAL NEUROSCIENCE 255, 256 (2001); INSIGHT AND PSYCHOSIS: AWARENESS OF ILLNESS IN SCHIZOPHRENIA AND RELATED DISORDERS (Xavier F. Amador & Anthony S. David eds., 2d ed. 2004). In addition, the condition is the "single largest reason why people with schizophrenia and bipolar disorder do not take their medications." *Anosognosia (Impaired Awareness of Illness): A Major Problem for Individuals with Schizophrenia and Bipolar Disorder*, TREATMENT ADVOC. CENTER (June 2005), [http://www.nami.org/Content/Microsites86/NAMI_Albuquerque/Home82/Current_Activities/NAMIWalks6/Briefing-anosognosia_\(05\).pdf](http://www.nami.org/Content/Microsites86/NAMI_Albuquerque/Home82/Current_Activities/NAMIWalks6/Briefing-anosognosia_(05).pdf).

90. See *supra* Part I.B.

91. A. Frank Johns, *Person-Centered Planning in Guardianship: A Little Hope for the Future*, 2012 UTAH L. REV. 1541, 1557 (2012).

92. Loretta M. Kopelman, *The Best Interests Standard for Incompetent or Incapacitated Persons of All Ages*, 35 J.L. MED. & ETHICS 187, 187 (2007). Kopelman points out use of the best interests doctrine "does not require ignoring all other duties . . . or others' interests in deciding what ought to be done for someone." *Id.* at 188 (emphasis in original).

93. For further discussion on the principle of autonomy, see Dora W. Klein, *Autonomy and Acute Psychosis: When Choices Collide*, 15 VA. J. SOC. POL'Y & L. 355, 388-89 (positing that mental illness

“substituted judgment” doctrine often relies on evidence of the patient’s preferences, as laid out through directives or other oral or written statements of preference, in order to guide a surrogate decisionmaker in advancing an individual’s treatment wishes if and when the individual becomes incapacitated at a later time.⁹⁴ If such evidence is not available, substituted judgment also asks the surrogate decisionmaker to “review the values of a formerly competent patient to determine” what to decide under the circumstances.⁹⁵ This section will examine how the doctrines underlie the creation of statutory schemes regarding medical treatment decisions and guide current decisionmaking.

B. STATUTORY SURROGATES ACT AS DECISIONMAKERS FOR INCAPACITATED PERSONS

The National Conference of Commissioners on Uniform State Laws created a statutory scheme that seeks to incorporate these doctrines in a uniform and comprehensive act. The Uniform Health-Care Decisions Act (“UHCDA”) lists a hierarchy of surrogates who can serve as decisionmakers once the primary physician⁹⁶ has determined that the individual lacks capacity (and there is no commonly used instrument like an advance directive to convey the patient’s instructions).⁹⁷ These surrogates are the individuals who will use either “substituted judgment” or “best interests” to make the decision for the incapacitated patient. The exact list and its contours can vary from state to state.⁹⁸ The UHCDA lists, in descending order of primacy: spouse, adult child, parents, sibling, close friend, and a residual exception for another adult who has exhibited special care and concern for the patient and is familiar

limits autonomy to a greater degree, or in a more important way, than does involuntary treatment, and that true autonomy must include “freedom from internal constraint”). Another response to the argument of applying a traditional principle of autonomy even in cases of serious mental illness comes from the Supreme Court: “One who is suffering from a debilitating mental illness and in need of treatment is neither wholly at liberty nor free of stigma.” *Addington v. Texas*, 441 U.S. 418, 429 (1979).

94. FURROW ET AL., *supra* note 22, at 1582.

95. *Id.*

96. The Act defines a “primary physician” as “a physician designated by an individual or the individual’s agent, guardian, or surrogate, to have primary responsibility for the individual’s health care or, in the absence of a designation or if the designated physician is not reasonably available, a physician who undertakes the responsibility.” UNIFORM HEALTH-CARE DECISIONS ACT, *supra* note 75, § 1.

97. *Id.* The act has been adopted in whole by six states (Alaska, Hawaii, Maine, Mississippi, New Mexico, and Wyoming) and forms the basis of several states’ laws with regard to advance directives. FURROW ET AL., *supra* note 22, at 1583.

98. New York’s Family Health Care Decisions Act lists a “close friend” on the surrogacy list. N.Y. PUB. HEALTH LAW § 2994-d(1)(f). The UHCDA does not list a “close friend” on the surrogacy list, but it does have a residual exemption for “an adult who has exhibited special care and concern for the patient, who is familiar with the patient’s personal values, and who is reasonably available.” UNIFORM HEALTH-CARE DECISIONS ACT, *supra* note 75, § 5(c).

with the patient's values.⁹⁹ While some states have not adopted such a surrogate list, that decision is not necessarily based on uncertainty about the need for, or legitimacy of, a surrogate decisionmaker list.¹⁰⁰ Instead, such a decision has notably been linked to pressure from groups concerned about issues such as same-sex couple recognition and whether the welfare of fetuses should be considered for incapacitated pregnant women.¹⁰¹

Statutory surrogate lists dovetail with the long-standing standard medical practice of seeking consent regarding an incapacitated person's treatment decisions from his or her close family members. Illustrating this view, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research suggested multiple reasons for traditional deference to family members, including that the family (1) is generally most concerned about the good of the patient; (2) deserves recognition as an important social unit that should be treated as a responsible decisionmaker in matters that intimately affect its members; and (3) will usually be most knowledgeable about the patient's goals, preferences, and values.¹⁰² Of course, these assumptions may not always accurately reflect particular relationships between family members related by blood or marriage,¹⁰³ but the Commission adopted a broader definition of family, as used within this Note.¹⁰⁴ Indeed, the purpose of the UHCDA as a whole, and the statutes it inspired, is to ensure that decisionmaking power stays with the patient when she has capacity, and that authority stays "within the family" otherwise.¹⁰⁵

Here, the decision to release information to the family caregiver should remain with the family caregiver. With the authority to make health care decisions that is afforded to a statutory surrogate, family caregivers can make the decision to release information about an individual during an involuntary psychiatric hold to themselves. The states that have already adopted this portion of the UHCDA allow the family caretaker to have access to information about the patient, but only

99. UNIFORM HEALTH-CARE DECISIONS ACT, *supra* note 75, § 5(b).

100. *See, e.g.*, Jacob Appel, *Finally Give N.Y. Families End-of-Life Decisionmaking Power*, N.Y. DAILY NEWS (Sept. 26, 2009, 1:29 AM), <http://www.nydailynews.com/opinion/finally-give-n-y-families-end-of-life-decisionmaking-power-article-1.402420>.

101. *Id.*

102. PRESIDENT'S COMM'N FOR THE STUDY OF ETHICAL PROBLEMS IN MED. & BIOMEDICAL & BEHAVIORAL RESEARCH, DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT: A REPORT ON THE ETHICAL, MEDICAL, AND LEGAL ISSUES IN TREATMENT DECISIONS 127 (1983); FURROW ET AL., *supra* note 22, at 1597 (noting family consent is "good medical practice (and good common sense) being subtly absorbed by the law").

103. *See infra* Part IV.D.2.

104. *See supra* note 4.

105. *See* UNIFORM HEALTH-CARE DECISIONS ACT, *supra* note 75, § 6 cmt. at 26 ("Decisions should whenever possible be made by a patient, or the patient's guardian, agent, or surrogate in consultation with the patient's health-care providers without outside interference.").

in limited circumstances; that is, where there is no advance directive, and then, depending on the doctrine used, when release of information is either in the best interests of the patient, or consistent with what the patient would have wanted if she was competent.

C. PSYCHIATRIC ADVANCE DIRECTIVES AS EVIDENCE OF INCAPACITATED PERSONS' PREFERENCES

Advance directives are other tools used to deal with the problem of serving the underlying goal of autonomy within the doctrine of substituted judgment when an individual lacks decisional capacity. They are statutorily created legal tools that enhance the autonomy of the patient when appropriate.¹⁰⁶ Advance directives refer to two different types of legal tools: individual instructions (for example, the living will) and durable powers of attorney (that is, the proxy or health care representative). Each can be completed separately, but people are often encouraged to complete both for comprehensive guidance. The UHCDA combines these tools. Whereas living wills are principally addressed at end of life decisionmaking,¹⁰⁷ the durable power of attorney essentially designates an agent or proxy to speak for the individual and make selected health care decisions.¹⁰⁸ Early on at common law, the power of attorney expired upon the “incapacity” of the principal.¹⁰⁹ Subsequently, the Uniform Probate Code was amended to allow such a power to remain in effect and even *become effective* upon an individual's incapacitation.¹¹⁰ Today, the vast majority of states have statutes that formally authorize the execution of durable powers of attorney for health care decisions.¹¹¹

An individual, while presumably having the requisite decisional capacity, creates an advance directive guiding a health care decision to be made at a later time, if and when that individual lacks decisional capacity. The individual instructions then guide the proxy in making a decision consistent with the individual's previously expressed choice. Thus, the proxy has power to make designated decisions for the individual. When an individual does not designate a proxy, statutory surrogate lists like the UHCDA designate the decisionmaker.¹¹²

106. See Leslie P. Francis, *Skeletons in the Family Medical Closet: Access of Personal Representatives to Interoperable Medical Records*, 4 ST. LOUIS U. J. HEALTH L. & POL'Y 371, 392–93 (2011).

107. FURROW ET AL., *supra* note 22, at 1592 (discussing rise of living will statutes or “right to die” legislation after the Karen Quinlan case). In some states, they only address people who are terminally ill, or those in a persistent vegetative state. *Id.*

108. *Id.* at 1593.

109. *Id.*

110. *Id.*

111. *Id.*; see, e.g., CAL. PROB. CODE § 4124(b) (West 1994) (“This power of attorney shall become effective upon the incapacity of the principal.”).

112. See *supra* Part III.B.

Proponents of the use of advance directives herald them for their autonomy-enhancing qualities.¹¹³ From an autonomy-centric point of view, advance directives do allow an individual to specify in advance whether certain representatives will have access to her medical records.¹¹⁴ However, that argument does not consider individuals with severe mental illness who lack insight into their illnesses and may be placed on involuntary psychiatric holds often.¹¹⁵ Without awareness of their illness, a patient in this situation is almost certain not to enact any instruction or create any durable power of attorney in another to receive information. In fact, in many of the severe cases, the individual may not even have the requisite decisional capacity to execute a valid individual instruction or a durable power of attorney. Furthermore, if she did, it stands to reason that she might do so merely to try to avoid treatment or dissemination of information regarding an illness that she might insist that she does not have.

Such severe cases arguably fall under a “need to know” approach to releasing PHI, because the information is relevant to current decisions about protecting and treating the patient now and in the future.¹¹⁶ A limitation on the information released to personal representatives on a “need to know” basis lacks substantive distinction when that personal representative is a family caregiver. The individual’s current symptoms, diagnosis, treatment plan options, and prognosis are all critical to the family caregiver so as to integrate her into the treatment plan and allow her to plan future accommodations. Finding out where a loved one is being kept on a 5150 is “need to know.”¹¹⁷ Even when the individual being held is not chronically in the hospital, a so-called “frequent flyer,”¹¹⁸ the rationale still applies. Important medication changes, follow-up doctor visits, additional medication changes, and what is happening to the patient in an involuntary psychiatric hold are all “need to know” details for the family caregiver for purposes of releasing PHI.

Some have argued that the doctrine of substituted judgment, which underpins the use of advance directives, is too speculative to be applied reliably, and that there is simply no way to protect the autonomy of a

113. See generally Francis, *supra* note 106 (examining advance directives as implemented by states and making recommendations).

114. *Id.* at 393.

115. Estimated at forty percent and fifty percent for cases of bipolar and schizophrenia, respectively. See *Anosognosia*, *supra* note 89.

116. Francis, *supra* note 106, at 395.

117. See *supra* note 3.

118. See Linda Paradiso, *Frequent Flyers: Treat Returning Psychiatric Patients Like Valued Customers*, NURSE.COM (May 27, 2013), <https://news.nurse.com/2013/05/27/frequent-flyer-treat-returning-psychiatric-patients-like-valued-customers/> (defining and criticizing the term used by hospital staff “to describe the patients who are admitted often to our psychiatric units”).

patient without decisional capacity.¹¹⁹ In the case where there is no possible method for establishing what the autonomous patient would do if she had capacity, bioethicists and courts move to the second principle of health care decisionmaking—beneficence—and rely on the doctrine of best interests to guide the decisionmaker.¹²⁰ This approach supports the adoption of the doctrine of best interests in this context, and allows the decisionmaker to have access to the PHI of the incapacitated individual.

Unfortunately, commentators have argued that advance care directives are more likely to be upheld when patients are refusing treatment and asserting autonomy rather than requesting treatment and beneficence, at least in the context of involuntary psychiatric holds.¹²¹ Thus, the analogous problem exists where advance directives that refuse to allow dissemination of information to anyone in the case of an involuntary psychiatric hold may be upheld whereas advance directives that direct a release of information may not. This problem suggests that advance directives for the direct release of information may be on a shakier practical ground, and thus, not an ideal avenue for attacking the problem. Nevertheless, the increased publicity and attention of advance directives suggests that these tools may form part of the solution¹²² because individuals could create advance directives to release PHI to family caregivers ahead of time.

IV. SOLUTIONS TO PROMOTE DISCLOSURE

A. COLLEGE ADMISSIONS PROCESSES COULD ENCOURAGE ADVANCED CONSENT TO RELEASE INFORMATION TO DESIGNATED FAMILY MEMBERS

Because advance directives are generally regarded as autonomy enhancing, they form a good starting point to discuss solutions. The

119. FURROW ET AL., *supra* note 22, at 1583; *see also* Rebecca S. Dresser, *Advance Directives, Self-Determination, and Personal Identity*, in *ADVANCE DIRECTIVES IN MEDICINE* 155, 157 (1989) (stating “future-oriented treatment decisions cannot be equated with the active choices of competent patients”); Louise Harmon, *Falling Off the Vine: Legal Fictions and the Doctrine of Substituted Judgment*, 100 *YALE L.J.* 1, 67 n.269 (1990).

120. *See, e.g.*, Roger B. Dworkin, *Getting What We Should From Doctors: Rethinking Patient-Autonomy and the Doctor Patient Relationship*, 13 *HEALTH MATRIX* 235, 284–86 (referring to doctrine of best interests as “[a] better way to decide what should be done for incompetent patient . . . [that] requires focus on reality, rather than fiction, and . . . considers many relevant interests, not just one”).

121. Justine A. Dunlap, *Mental Health Advance Directives: Having One’s Say?*, 89 *KY. L.J.* 327, 356–58 (2000) (noting constitutional right to refuse treatment, but not to obtain treatment); *see also* Margo Flug, *No Commitment: Kendra’s Law Makes No Promise of Adequate Mental Health Treatment*, 10 *GEO. J. POVERTY LAW & POL’Y* 105, 121 (2003) (“Proxies are generally viewed as a means for patients to refuse unwanted treatment rather than to demand desired treatment.”).

122. President Barack Obama purportedly became the first U.S. president to acknowledge he has an advance directive. President Barack Obama, Remarks by the President in an AARP Tele-Town Hall on Health Care Reform (July 28, 2009), *available at* http://www.whitehouse.gov/the_press_office/Remarks-by-the-President-in-AARP-Tele-Town-Hall-on-Health-Care-Reform/.

Family Education Rights and Privacy Act (“FERPA”)¹²³ currently allows post-secondary educational institutions to “disclose information from education records to any person whose knowledge of the information is necessary to protect the health or safety of the student or other individuals.”¹²⁴ This FERPA exception is limited to the period of the emergency and the information needed to address the emergency.¹²⁵

Post-secondary educational institutions often condition enrollment on meeting certain medical requirements.¹²⁶ Accordingly, post-secondary educational institutions could strongly encourage students during enrollment to sign a waiver to explicitly authorize the release of necessary health information to their parents (or other appropriate designated caregiver) in the event of a medical emergency that involves serious medical or mental health conditions in which treating professionals or school authorities reasonably believe that involvement of the identified family member would be in the student’s best interest. The release could limit the amount of information to only as much as necessary to serve that student’s best interest. Such an initiative is strongly supported by the reality that many mental illnesses manifest during late teenage years, precisely the time that many students in the United States enter and attend college.¹²⁷

An optional advance directive will have drawbacks.¹²⁸ While proponents of an optional waiver may argue that merely bringing up the topic is a sufficient enough impetus to have students and parents agree to sign such a waiver, experience counsels that young adults often think they are “invincible.”¹²⁹ The motivation to deny the possibility of illness is

123. For general information on FERPA, see *Family Education Rights and Privacy Act (FERPA)*, U.S. DEPT. EDUC., <http://www2.ed.gov/policy/gen/guid/fpco/ferpa/index.html>.

124. 34 C.F.R. § 99.36 (2010).

125. *Faculty Handbook Provides Guidance in Assisting Students in Distress; FERPA Privacy Exceptions Permit Faculty Intervention/Referral*, 32 DEV. MENTAL HEALTH L. 4, 7 (2013).

126. *State Information: Meningococcal Prevention Mandates for Colleges and Universities*, IMMUNIZE.ORG, <http://www.immunize.org/laws/menin.asp> (showing most states require vaccination as a condition of enrollment). Even before the enactment of the Affordable Care Act, “about 30 percent of colleges nationwide required students to have health insurance . . . and some states also [had] health insurance requirements for college students.” U.S. GOV’T ACCOUNTABILITY OFFICE, *GAO-08-389, Health Insurance: Most College Students Are Covered Through Employer-Sponsored Plans, and Some Colleges and States Are Taking Steps to Increase Coverage* (Mar. 2008), available at <http://www.gao.gov/new.items/do8389.pdf>.

127. See *Mental Illness Exacts Heavy Toll*, *supra* note 44 (“Half of all lifetime cases begin by age 14; three quarters have begun by age 24. Thus, mental disorders are really the chronic diseases of the young.”).

128. An alternative proposal would consist of a mandatory advance directive. While such a requirement resolves the drawbacks of an optional form, it also raises constitutional questions. The Author suggests a nonmandatory option for its decreased risk of litigation and its comparative ease of implementation now, and the exploration of a mandatory requirement in the near future.

129. Alexandra Petri, *President Obama Is Funny, Mean, Promoting Healthcare.gov on “Between Two Ferns”*, WASH. POST (March 11, 2014) <https://www.washingtonpost.com/blogs/compost/wp/2014/03/11/president-obama-is-funny-mean-promoting-healthcare-gov-on-between-two-ferns/> (providing

even stronger when dealing with stigmatized illnesses such as major depression, schizophrenia, bipolar disorder, and so forth.¹³⁰ It is a rare student (or parent) who contemplates (or even wants to contemplate) the possibility of such illness. And talking to someone during her difficult transition from adolescence to young adulthood is already difficult for families.¹³¹ However, the implementation of this advance directive would further enhance the existing autonomy rationale underlying the use of advance directives in health care planning. Creating an advance directive triggers contemplation and planning. This planning process also gives the young person choice in assigning who receives her PHI in the event of an involuntary psychiatric hold or similar medical emergency, thus directly addressing any fears about a possible loss of autonomy associated with an automatic release of PHI. Thus, it empowers her to choose the individuals who she feels are most likely to be effective caregivers should the situation present itself. The college advance directive also allows the young person to exclude relatives whom she does not want to have access to her information, for reasons including strained relations or a judgment that certain individuals would not be effective caregivers or productive in the treatment process.

Although some critics may argue that encouraging students to create an advance directive violates HIPAA's underlying policy, this requirement actually addresses critics' concerns regarding individual autonomy. If HIPAA's underlying justification is to protect an individual's choice, broadly defined, then such a rule would seem to invite litigation. However, if HIPAA's underlying justification is correctly seen as empowering individuals in making their health care choices, then the impetus of such a requirement actually effectuates the exercise of choice. The individual is empowered to designate caregivers to receive information at an earlier time when she has more capacity, as opposed to waiting until her decisional capacity is called into question by an acute psychotic episode and manifestations of mental illness, then leaving the designation and decision up to a statutory surrogacy list. This

link to video clip); see also Kathrine Vargas, *Why Do Young People Need Obamacare?*, WHITEHOUSE.GOV (Sept. 28, 2013, 11:26 AM), <https://www.whitehouse.gov/blog/2013/09/28/why-do-young-people-need-obamacare>.

130. "Stigma among emerging adults persists the notion that it is shameful to suffer from a behavioral health issue and that coming forward to seek diagnosis and treatment will limit academic and vocational achievement. Social stigma leads to needless embarrassment, especially when associated with peer groups. It is not surprising, to find that only 1 in 3 students that need mental health care will actually seek assistance." Ashley Clement, *Breaking Down Barriers to Mental Health Services in Emerging Adulthood*, 13 HARV. HEALTH POL'Y REV. 32, 32 (2012).

131. Developmental psychologists, mental health professionals, and other scholars now refer to the developmental stage between adolescence and early adulthood as "emergent adulthood." Jeffrey J. Arnett, *Emerging Adulthood: A Theory of Development from the Late Teens Through the Twenties*, 55 AM. PSYCHOLOGIST, 469, 470 (2000).

proposal's strongest upside is its incorporation of the traditional understanding of autonomy.

The real downside to relying on this advance directive solution is that it only reaches a fraction of the undefined demographic that will at some point go into an involuntary psychiatric hold. Not everyone in the United States attends post-secondary schools.¹³² Furthermore, the initiative would not reach anyone who has already moved passed the enrollment process at a college or university. And as it is optional, many students may not choose to create an advance directive. Thus, this proposal is not ideal, because leaving out those broad swaths of society fails to provide a comprehensive solution. Nevertheless, it is still an option available to reach a large number of college-bound youths.

B. EXPANSIVE INTERPRETATION OF "TREATMENT" COULD INCLUDE COMMUNICATIONS WITH FAMILY CAREGIVERS

As discussed above, there is ample evidence to support the finding that family members are an important part of the treatment process in treating an individual with severe mental illness.¹³³ If the family caregivers' role is recognized as that of a treatment provider,¹³⁴ then the release of information is permitted under current HIPAA language.¹³⁵ However, the release of information under the "treatment" provision of HIPAA is still permissive.¹³⁶ That means providers still run into the same pitfalls that prevent disclosure of information today: financial burden, staff burden, and institutional inertia.¹³⁷ While the DHHS can issue more guidance and education to providers in an effort to try to counteract those barriers, previous guidance letters to treatment providers have proven to be unsuccessful in changing provider policy. The "treatment provider" solution still suffers from the lack of a requirement on the providers to comply and release information. If this solution is to be

132. In October 2013, 65.9% of 2013 high school graduates were enrolled in colleges or universities. U.S. BUREAU OF LABOR STATISTICS, *College Enrollment and Work Activity of 2013 High School Graduates* (Apr. 16, 2014, 10:00 AM), <http://www.bls.gov/news.release/hsgec.nro.htm>.

133. *See supra* note 33.

134. *See, e.g.*, Janki Shankar & Senthil Sonai Muthuswamy, *Support Needs of Family Caregivers of People Who Experience Mental Illness and the Role of Mental Health Services*, FAMILIES IN SOCIETY, J. CONTEMP. SOC. SERVICES 302 (2007) ("Family caregivers are an irreplaceable resource for the mental health services system and the pillars on which the system currently rests."); *Family Caregiving*, AM. PSYCHOL. ASS'N, <http://www.apa.org/about/gr/issues/cyf/caregiving-facts.aspx> (describing general family caregiving duties as including medical care adherence monitoring).

135. 45 C.F.R. § 164.506 (2014).

136. Some question might remain as to whether some of the PHI of an individual on an involuntary psychiatric hold falls under the "psychotherapy notes" characterization, which requires authorization of the individual. *See* 45 C.F.R. § 164.508(A)(2) (2014). For the most part, however, these categories of PHI are well-defined. *See HIPAA Privacy Rule and Sharing Information, supra* note 8 (listing various categories of information that would not fall under "psychotherapy notes").

137. *See supra* Part I.B.

further developed, the focus should remain on devising a requirement that will ensure provider compliance.

C. AN AMENDMENT TO THE HIPAA PRIVACY RULE CAN CLARIFY THAT PHYSICIANS CAN RELEASE PROTECTED HEALTH INFORMATION TO A FAMILY CAREGIVER

A more straightforward and inclusive approach to the problem is to designate a family caretaker as a personal representative within the provisions of the Privacy Rule. There is proposed legislation that would designate a family caretaker as a “personal representative” for the Privacy Rule’s purposes, among other purposes.¹³⁸ Congressman Tim Murphy of Pennsylvania introduced legislation in the 2013–2014 congressional term to clarify the Privacy Rule and “the Family Educational Rights and Privacy Act so physicians and mental health professionals can provide crucial information to parents and caregivers about a loved one who is in an acute mental health crisis to protect their health, safety, and well-being.”¹³⁹ Congressman Murphy reintroduced this bill in the 114th session of Congress.¹⁴⁰ Under this proposal, a “caregiver” of an individual with a serious mental illness is defined as an immediate family member, who assumes primary responsibility for providing a basic need of such individual, or a personal representative determined by the laws of the state.¹⁴¹ The bill also defines “an individual with serious mental illness” as someone (1) eighteen years or older (2) who has been diagnosed (within one year of the date of information disclosure) with “a mental, behavioral, or emotional disorder” that meets the diagnostic criteria of the *Diagnosics and Statistical Manual of Mental Disorders*, and (3) “results in functional impairment of the individual that substantially interferes with or limits one or more major life activities of the individual.”¹⁴² The proposed amendment to HIPAA would directly allow a family caretaker to receive PHI about an individual who is held on an involuntary psychiatric hold without requiring the individual’s explicit consent. The proposal only affects adults eighteen years and older because before then, adult caretakers such as parents or guardians of an

138. The Helping Families in Mental Health Crisis Act, H.R. 3717, 113th Cong. § 301(a) (2013), available at <http://murphy.house.gov/uploads/HR3717%20Bill%20Text.pdf>.

139. See *supra* note 38; see also H.R. 3717 113th Cong. § 301(a).

140. *Reps. Murphy and Johnson Reintroduce the Helping Families in Mental Health Crisis Act*, CONGRESSMAN TIM MURPHY (June 4, 2015), <http://murphy.house.gov/latest-news/rep-murphy-and-johnson-reintroduce-the-helping-families-in-mental-health-crisis-act/>.

141. *Id.* Murphy’s bill indicates basic needs include “food, clothing, shelter, health, or safety,” as well as “assum[ing] the responsibility of co-signing a loan with the individual.” H.R. 3717 113th Cong. §§ 705(3)(D), 302(k)(2)(A).

142. H.R. 3717 113th Cong. § 302(k)(2)(C).

individual generally have access to their health information.¹⁴³ Murphy's proposal also includes caregiver access to certain education records under FERPA when the treating mental health professional "reasonably believes such disclosure to the caregiver is necessary to protect the health, safety, or welfare" of that individual or others.¹⁴⁴ This additional piece of informational access allows the caregiver to have access to medical treatment-related documents that high schools and post-secondary educational institutions will hold regarding incidents, treatments, and evaluations that occur at school.

This approach has a number of advantages. It easily works its way into the language of the existing Privacy Rule. Providers can easily understand that once the Privacy Rule recognizes someone as a "personal representative," that representative is entitled to receive the individual's PHI, subject to the endangerment exception.¹⁴⁵ The proposed bill also requires the provider to consider the family caregiver a "personal representative" when the provider "reasonably believes it is necessary . . . to protect the health, safety, or welfare of such individual or the safety of one or more individuals."¹⁴⁶ Also, the inclusion of access to records under FERPA gives the caretaker more information regarding the nature of the individual's illness, further facilitating the caregiver's ability to assist with treatment.

One possible criticism of the proposal rests on the notion that allowing all "immediate family members" the designation of "personal representative" for HIPAA purposes could lead to dissemination of information to family members who have no role in the treatment of the individual or her life generally. That would not address the real problem this Note seeks to remedy, that of providing important information to actual caretakers, and may actually complicate matters further for the individual. One response to this criticism is to remove the "immediate family member" clause because the subsequent clause already includes the established family caregiver—"an individual who assumes primary responsibility for providing a basic need of such individual."¹⁴⁷ Thus, "immediate family member" becomes duplicative when the immediate family member actually assumes primary responsibility for caring for the individual. A second response is that the additional disclosure would not

143. 45 C.F.R. § 164.502(g)(3)(i) (2014). This depends on the particular governing state law. *See* Standards for Privacy of Individually Identifiable Health Information, 65 Fed. Reg. 82582 (Dec. 28, 2000) (to be codified at 45 C.F.R. §§ 160, 164) ("Where states have . . . explicitly acted, for example, to authorize disclosure, defer the decision to disclose to the discretion of the health care provider, or prohibit disclosure of minor's protected health information to a parent, the rule defers to these decisions to the extent that they regulate such disclosures.").

144. H.R. 3717 113th Cong. § 301(a).

145. *Id.*

146. *Id.*

147. *Id.*

be harmful given HIPAA's existing "endangerment exception" protection against releasing information that would endanger the individual.¹⁴⁸

D. IMPORTANT CONSIDERATIONS

With any of the three previously proposed solutions, other existing HIPAA provisions would still apply additional considerations to the release of information. The first provision provides guidance on how much PHI is released. The second provision serves as an important exception to inappropriate release of PHI.

1. *The Breadth of the Protected Health Information Released Would Fall Under Exceptions to the Minimum Necessary Rule*

Under HIPAA, the amount of PHI released is generally limited to the "minimum amount of protected health information needed to accomplish the intended purpose of the use, disclosure, or request."¹⁴⁹ However, this "minimum necessary" rule does not apply when a health care provider requests or receives information for treatment purposes, and an individual's personal representative requests the information, or when disclosure is required by law.¹⁵⁰ If a release of PHI to a designated caregiver is indicated by an advance directive, the caregiver can be considered the individual's personal representative. If informing family members is considered treatment under HIPAA, then that release of information is for treatment. Under Congressman Murphy's proposal, the disclosure is made to the individual's personal representative. Thus, all three of this Note's proposed solutions fall within the exceptions to the "minimum necessary" limit on information disclosure. These exceptions recognize the need for wide disclosure for treatment purposes, because the PHI encompasses much important information to take into consideration when formulating treatment plans involving a family caregiver.

On the other hand, allowing access to an individual's entire PHI may be inappropriate and impractical. First, allowing access to information unrelated to an individual's mental illness diagnosis and caretaking needs appears extraneous to the purpose of these proposed exceptions, and unnecessarily encroaches on an individual's privacy with respect to that extraneous information. Second, providers will need guidance on what amount of information can be released so as to protect this privacy interest. One possibility is to include language that the "minimum necessary" rule applies to these exceptions, which would limit this to the purpose of the disclosure. A second option is to include new language

148. See *infra* Part IV.D.2.

149. SUMMARY OF THE HIPAA PRIVACY RULE, U.S. DEP'T OF HEALTH & HUM. SERVS. 10 (May 2003).

150. *Id.*

that limits the information released to that “necessary for the family member to perform caregiving and supportive roles.”

2. *A Safety Rationale for Cabining PHI Disclosure to Family Members Generally Already Applies*

One consideration that must be weighed against both statutory surrogate lists and expansion of HIPAA to release information to informal family caregivers is problematic family circumstances. The law generally assumes that parents, for example, will act in the best interests of a child.¹⁵¹ Biological family members need not be completely altruistic in order to want to achieve the “best interests” of their family member with mental illness. However, there are undoubtedly situations where past problems, or fundamental differences in values have created such tension and discord that a biological family member may not care about the best interests of another, or may actually want to harm them. In other situations, biological family members may not understand the information that they receive, or may not believe the diagnosis or illness itself.¹⁵² These scenarios present the distinct possibility that the biological family member may not want to be part of the treatment team, or would currently be an ineffective member of the team.

In such cases, the health care provider should be able to withhold the release of information if, in her professional judgment, the particular family member’s involvement would have a detrimental effect on the course of the treatment or on the best interests of the patient. In the context of a health care decision for an adolescent, the Supreme Court recognized in *Parham v. J.R.* that a parent’s authority to make a decision must be “subject to a physician’s independent examination and medical judgment.”¹⁵³ The Privacy Rule already codifies this important standard. The Privacy Rule itself allows for the health care provider to use her professional judgment to deny a personal representative access to PHI if the minor “may be endangered by treating the person as the personal representative, and . . . it is not in the best interests of the patient”¹⁵⁴ Thus, the Privacy Rule already affords the health care provider the ability to avoid automatically releasing information to someone when, in essence, that someone is not acting as an actual “caregiver” of the patient. Furthermore, in addition to the health records of the individual, health care providers also have access to other public records that may

151. See *Parham v. J.R.*, 442 U.S. 584, 602 (1979) (noting that the “natural bonds of affection lead parents to act in the best interests of their children”).

152. See, e.g., Boldt, *supra* note 46, at 76 (“Steve is reluctant to consent to the disclosure of this information to his parents because of his father’s intolerant attitude toward the use of alcohol and other drugs.”).

153. 442 U.S. at 604.

154. See 45 C.F.R. § 164.502(g)(5) (2014); see also *HIPAA Privacy Rule and Sharing Information*, *supra* note 8, at n.2.

indicate a negative relationship (for example, a restraining order) and the health care provider's own interactions with the person claiming to be the caregiver and seeking access to the information based on being a caregiver. The provider can and should rely on a review of this evidence to arrive at her reasonable belief that a particular request for information falls under the endangerment exception.

CONCLUSION

The HIPAA Privacy Rule seeks to afford people the right and ability to control access to their sensitive health care information. Generally, that is a good thing. But the Privacy Rule does make a notable exception for when an individual lacks capacity to make the decision to release that information. In the case of involuntary psychiatric holds, individuals often lack decisional capacity because of the acute episode, whether an initial episode or a chronic episode, that necessitated their psychiatric hold. Due to the current permissive nature of the incapacity exception, providers routinely refuse to release information to the family caregivers involved in the individual's current and long-term health. Because of the incentives for health care providers, they consistently avoid disclosure without express consent from the individual on the involuntary psychiatric hold. In order to empower families and the community to better deal with these difficult mental illness challenges, as well as serve the best interests of the patients themselves, the "default" of health care providers should be set in the interest of disclosure to family caregivers as part of treatment. This recognizes the reality of many severe mental illnesses, and helps health care providers—professionals and family—help someone in need.
