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Office of Civil Rights
U.S. Department of Health and Human Services
200 Independence Avenue, S.W.
Washington, D.C. 20201

submitted via <http://www.regulations.gov>

RE: HHS Docket No. HHS-OCR-2021-0006-0001
45 C.F.R. §§ 160, 164
RIN No. 0945-AA00



Comment of the American Civil Liberties Union in Opposition to 86 Fed. Reg. 6446; Modification to the HIPAA Privacy Rule to Support, and Remove Barriers to, Coordinated Care and Individual Engagement

Dear Ms. Gordon-Nguyen,

The American Civil Liberties Union (ACLU) writes to offer comments in response to the Department of Health and Human Services' January 21, 2021, Notice of Proposed Modifications to the HIPAA Privacy Rule to Support, and Remove Barriers to, Coordinated Care and Individual Engagement, published at 86 Fed. Reg. 6446.¹

We firmly oppose the proposed changes to the Privacy Rule that would relax the standard by which “covered entities” may share individuals’ sensitive health information without consent—including with police, the family regulation system (also sometimes called the “child welfare” system) and other third parties.² The Department seeks through these modifications to “encourage covered entities to use and disclose [protected information] more broadly in scenarios that involve SUD (substance use disorder), SMI (serious mental illness), and emergency situations.”³ These changes would needlessly infringe on

¹ 86 Fed. Reg. 6446 (Jan. 21, 2021) (hereinafter, “Notice”), *available at* <https://www.regulations.gov/document/HHS-OCR-2021-0006-0001>. The Department subsequently published an extension of the comment period. *See* 86 Fed. Reg. 13683 (Mar. 10, 2021), *available at* <https://www.regulations.gov/document/HHS-OCR-2021-0006-0003>.

² *See* 86 Fed. Reg. 6475, 6477.

³ *Id.* at 6480.



individuals' expectation of privacy in their medical information, and the costs of this diminished privacy would not be borne equally.

While patients, family members, or members of the public may in some cases have an interest in the prompt transmission of information under HIPAA, that interest is more than satisfied by existing laws and regulations—including the current HIPAA Privacy Rule. On the other hand, inviting healthcare providers to more liberally share patient information will create harms that the Department does not contemplate in its proposal. The expectation that provider-patient communications will remain confidential is a cornerstone of effective healthcare treatment. Particularly for people of color, people with disabilities, and people who use drugs, the proposed changes to the Privacy Rule will undermine that confidentiality out of proportion with any demonstrated need and will chill patients from fully engaging with needed care. To the extent that the proposed modifications may increase vulnerable patients' contacts with law enforcement, they also present a serious risk to those patients' safety and health. The Department should not move forward with rule changes that are both not justified by a documented need, and will create particularly acute perils for some patients.

I. The Department's Proposed Modifications to the Privacy Rule Would Weaken Already Permissive Standards, Increase Vulnerable Patients' Contacts with Police, & Chill Patient Engagement.

As the Department recognizes, the Privacy Rule already contemplates nonconsensual disclosures in emergencies and other circumstances.⁴ Providers enjoy a broad mandate under the Rule to decide whether a situation warrants breaching patient privacy, but their authority is generally tethered in some way to their expertise and the urgency of the situation at hand. This is as it should be, and a watered-down standard would leave patient privacy significantly under-protected against overzealous disclosures.

A. The Current Standards Governing Emergency Disclosures Appropriately Balance Patient Privacy Against Other Interests and Should Be Maintained.

Of particular concern is the Department's proposal to lower the standard for a covered entity "to use or disclose an individual's

⁴ See, e.g., 45 C.F.R. §§ 164.510(b)(3), 164.512(j)(1)(i)(A).



[protected health information] based on” a perceived threat of harm.⁵ The Privacy Rule currently permits such disclosures only when “necessary to prevent or lessen a *serious and imminent* threat to the health or safety of a person or the public.”⁶ Through its proposal, the Department seeks to replace this standard—which already incorporates considerable deference to the judgment of providers⁷—with a significantly more permissive one, which would allow disclosures when harm is merely “reasonably foreseeable.”⁸ This substitution invites providers to err on the side of indiscretion, exposing patients’ sensitive information whenever harm might occur at some distant, unknown future point. This, in turn, will chill vulnerable patients from accessing care, by undermining their trust and potentially exposing them to risky encounters with police, the family regulation system, or other government interventions.

As stated above, the HIPAA Privacy Rule currently allows healthcare providers to “use or disclose” a patient’s protected information if “necessary to prevent a serious and imminent threat to the health or safety of a person or the public.”⁹ Covered entities under HIPAA benefit from a great deal of deference in administering this standard; the Privacy Rule includes a “presumption of good faith belief” for providers who base their perception of threat on either their “actual knowledge” or “a credible representation by [someone] with apparent knowledge or authority.”¹⁰ And HHS clearly advertises healthcare providers’ broad authority to make judgments and disclose information,¹¹ and touts its choice to provide leeway to providers by not defining the term “imminent” in the text of the Rule in order to avoid unduly “restricting uses and disclosures under this provision.”¹² In other words, the current regime does not constitute an impediment to

⁵ 86 Fed. Reg. 6478.

⁶ 45 C.F.R. § 164.512(j)(1)(i)(A) (emphasis added).

⁷ See, e.g., U.S. Dep’t of Health and Human Servs., FAQ 3002 (Jun. 8, 2020), <https://www.hhs.gov/guidance/document/faq-3002-what-constitutes-serious-and-imminent-threat-would-permit-health-care-provider> (“HIPAA expressly defers to the professional judgment of health professionals in making determinations about the nature and severity of the threat to health or safety posed by a patient.”)

⁸ 86 Fed. Reg. 6482.

⁹ 45 C.F.R. § 164.512(j)(1)(i)(A).

¹⁰ *Id.* § 164.512(j)(4).

¹¹ See, e.g., Letter from Leon Rodriguez, Director of the Office for Civil Rights, Dep’t of Health and Human Servs. (Jan. 15, 2013), *available at* <https://www.hhs.gov/sites/default/files/ocr/office/lettertonationhcp.pdf>; HHS, FAQ 3002, *supra* note 7.

¹² See 86 Fed. Reg. 6525.



nonconsensual disclosures when necessary. To stay within its bounds, a provider need only believe, consistent with her training and based on some information, that harm is forthcoming, and that sharing a patient’s protected information can help to stop or mitigate it.

As the Department recognizes, the Privacy Rule is already flexible enough to accommodate a statutory or judicially imposed “duty to warn” third parties¹³—no additional flexibility is needed. Without a requirement that harm be imminent, the Rule would fail to distinguish between emergency disclosures and disclosures based only on suspicion. Allowing providers to rely on conjecture and what they deem to be a “reasonably foreseeable” threat is a recipe for disaster, particularly when it comes to people with mental health disabilities. For example, research shows that mental and behavioral health professionals do not have any particular skills to predict risk, danger, or suicide.¹⁴ The Department suggests that it intends only to “clarify” the existing standard, rather than change it,¹⁵ but the proposal would in fact usher in a significant rollback of patients’ privacy rights. The imminence requirement appropriately permits providers to pierce patient confidentiality only when truly necessary; a lesser standard would risk unjustified harm to the provider-patient relationship and to patients’ health and safety. Providers would have virtually unlimited discretion to disclose protected health information (PHI) based on mere speculation rather than concrete and immediate risks.

In addition to lowering the standard for emergency disclosures from “imminent” to “reasonably foreseeable,” the Department proposes to further add “an express presumption that [a provider] has met the [new] standard.”¹⁶ As justification for its proposal, HHS offers that providers may make more timely disclosures, potentially averting

¹³ *Id.* at 6478 & n.202; 65 Fed. Reg. 82462, 82538 (Dec. 28, 2000); *see also*, e.g., *Tarasoff v. Bd. Regents of the Univ. of Cal.*, 551 P.2d 334 (Cal. 1976) (en banc).

¹⁴ Am. Psychological Ass’n, *After Decades of Research, Science Is No Better Able to Predict Suicidal Behaviors* (Nov. 15, 2016), <https://www.apa.org/news/press/releases/2016/11/suicidal-behaviors> (“Our analyses showed that science could only predict future suicidal thoughts and behaviors about as well as random guessing. In other words, a suicide expert who conducted an in-depth assessment of risk factors would predict a patient’s future suicidal thoughts and behaviors with the same degree of accuracy as someone with no knowledge of the patient who predicted based on a coin flip. This was extremely humbling—after decades of research, science had produced no meaningful advances in suicide prevention.”).

¹⁵ 86 Fed. Reg. 6482.

¹⁶ *Id.* at 6483.



situations in which a covered entity would have shared patient information “but for [their] uncertainty regarding whether a threatened harm is ‘imminent.’”¹⁷ But the Department provides no evidence that such situations are common. It also does not substantiate its suggestion that the current Rule hinders information sharing, nor provide support for the claim that increased information sharing would actually be effective at preventing harm. Instead, the notice states simply that “in the wake of the incidents of mass violence in recent years, such as shootings and acts of terrorism, the Department has heard anecdotes claiming that HIPAA impedes health care providers from disclosing PHI.”¹⁸ This is not enough. The Administrative Procedures Act (APA) requires a federal agency conducting a notice-and-comment rulemaking to “examine the relevant data and articulate a satisfactory explanation for its action including a ‘rational connection between the facts found and the choice made.’” *Motor Veh. Mfrs. Ass’n v. State Farm Mut. Auto. Ins. Co.*, 463 U.S. 29, 43 (1983) (citing *Burlington Truck Lines, Inc. v. United States*, 371 U.S. 156, 168 (1962)). Moreover, there is a presumption “against changes in current policy that are not justified by the rulemaking record.” *Id.* at 42. The citation to anecdotal reports here is insufficient to explain the changes suggested, especially in light of its potential costs. Further, lowering the standard for providers to estimate risk of harm where a presumption of “good faith belief” is already present would effectively render emergency disclosures pursuant to 45 C.F.R. § 164.512(j)(1) unreviewable under HIPAA. Incorporating a “presumption of good faith” for other categories of disclosure that are currently permitted only “in the exercise of professional judgment” would have a similar effect.¹⁹ Put simply—if disclosures under HIPAA are presumed to be made on a “good faith” basis and not otherwise tied to providers’ exercise of judgment, then the Privacy Rule would be rendered useless. Instead, the standard for emergency disclosures should be maintained.

¹⁷ *Id.*

¹⁸ *Id.* at 6479

¹⁹ The Notice seeks to replace “professional judgment” with a standard based on “good faith belief” at 45 C.F.R. §§ 164.502(g)(3)(ii)(c) (disclosures to parents or guardians who are not a patient’s “personal representative”), 164.510(a)(3) (facility directories), 164.510(b)(2)(iii) (emergency contacts), 164.510(b)(3) (emergencies and incapacity), 164.514(h)(2)(iv) (verifying requestor’s identity). *See* 86 Fed. Reg. 6481–82.

B. Contacts Between Patients and Law Enforcement & The Family Regulation System Themselves Pose Safety Risks, Particularly for People of Color, People with Disabilities, and People Who Use Drugs. They Should Therefore Be Minimized.

Several of the Department’s proposed modifications risk facilitating the disclosure of patient information beyond patients’ consent. We turn now to those proposals and illustrate their risks, especially when sensitive information may reach police or actors in the family regulation system.



The emergency disclosure provision discussed above allows for disclosures to “a person or persons reasonably able to prevent or lessen” a threat, which will sometimes include police. But contact between patients and police itself poses significant risks,²⁰ which the Department does not contemplate in its proposal. Particularly for people of color and those with disabilities, law enforcement contacts carry heightened risks of injury and death, and can also interfere with individual and community health outcomes.²¹ Instead of inviting these harms, the Department should call on providers to avoid involving law enforcement whenever possible and instead provide assistance in a manner consistent with patient privacy and the ethical obligation to do no harm.

Though police are often called on to respond to mental health crises, they are ill-equipped to safely and effectively provide the care people need in these situations. All too often, the consequences of police involvement are fatal. By some estimates, people with untreated serious mental illnesses are sixteen times likelier than other civilians to be killed by police during an encounter.²² The killings by police of

²⁰ See *Fatal Force*, Wash. Post, <https://www.washingtonpost.com/graphics/investigations/police-shootings-database/> (documenting incidents of fatal shootings by police; as of May 5, 2021, the Post recorded 985 people shot and killed by police in 2021 alone).

²¹ See, e.g., American Public Health Ass’n, Policy No. 201811: Addressing Law Enforcement Violence as a Public Health Issue (Nov. 13, 2018), <https://apha.org/policies-and-advocacy/public-health-policy-statements/policy-database/2019/01/29/law-enforcement-violence>; Abigail Abrams, *Black, Disabled and at Risk: The Overlooked Problem of Police Violence Against Americans with Disabilities*, Time (Jun. 25, 2020), <https://time.com/5857438/police-violence-black-disabled/>; see also discussion *infra*.

²² See Treatment Advocacy Ctr., *Overlooked and Undercounted: The Role of Mental Illness in Fatal Law Enforcement Encounters* (Dec. 2015), available at

Daniel Prude,²³ Walter Wallace Jr.,²⁴ and Deborah Danner,²⁵ to name but a few, demonstrate that police are the inappropriate actors to intervene during behavioral crises.

Police also inflict violence on Black people and people of color at much higher rates than white people.²⁶ One study has found that young unarmed male victims of deadly force by police are more than thirteen times more likely to be Black than white.²⁷ Police use of force now ranks among the leading causes of death for young men of color.²⁸ Far from reliably mitigating risk of harm, involving police significantly *increases* the risk of harm to members of overpoliced communities.

Similarly grave disparities characterize police-initiated involuntary holds in psychiatric emergency rooms, another traumatic and disempowering consequence that could result from overzealous emergency disclosures to law enforcement.²⁹ Black people, indigenous people, and other people of color are more likely to be over-policed and less likely to have access to quality mental healthcare than white



<https://www.treatmentadvocacycenter.org/storage/documents/overlooked-in-the-undercounted.pdf>.

²³ Edgar Sandoval, *Daniel Prude Was in 'Mental Distress.' Police Treated Him Like a Suspect*, N.Y. Times (Oct. 9, 2020), <https://www.nytimes.com/2020/10/09/nyregion/daniel-prude-rochester-police-mental-health.html>.

²⁴ Jenny Gross, *What We Know About the Death of Walter Wallace, Jr.*, N.Y. Times (Nov. 4, 2020), <https://www.nytimes.com/article/walter-wallace-jr-philadelphia.html>.

²⁵ The Editorial Bd., *The Death of Deborah Danner*, N.Y. Times (Oct. 20, 2016), <https://www.nytimes.com/2016/10/21/opinion/the-death-of-deborah-danner.html>.

²⁶ See American Civil Liberties Union, *The Other Epidemic: Fatal Police Shootings in the Time of COVID-19* (2020), <https://www.aclu.org/report/other-epidemic-fatal-police-shootings-time-covid-19>.

²⁷ Ulrich Schimmack & Rickard Carlsson, *Young Unarmed Nonsuicidal Male Victims of Fatal Use of Force Are 13 Times More Likely to Be Black Than White*, 117 Proceedings of the Nat'l Acad. of Scis. 1263 (Jan. 2020), available at <https://doi.org/10.1073/pnas.1917915117>.

²⁸ Frank Edwards, Hedwig Lee, & Michael Esposito, *Risk of Being Killed by Police Use of Force in the United States by Age, Race-Ethnicity, and Sex*, 116 Proceedings of the Nat'l Acad. of Scis. 16793–98 (August 2019), available at <https://doi.org/10.1073/pnas.1821204116>.

²⁹ Christie Thompson, *When Going to the Hospital Is Just as Bad as Jail: New LawsUIT Claims Black Americans with Mental Illnesses Are Being Forced into Traumatic Emergency Room Stays*, The Marshall Proj. (Nov. 8, 2020), <https://www.themarshallproject.org/2020/11/08/when-going-to-the-hospital-is-just-as-bad-as-jail>.



Americans.³⁰ They are consequently overrepresented in psychiatric inpatient care,³¹ as are people experiencing homelessness and those who have had contact with the criminal legal system.³² Unnecessary hospital holds are inherently stigmatizing³³ and would run counter to HHS’s intention to avoid “false and harmful stereotypes about individuals with SMI or SUD.”³⁴ The Department should not court these harms by inviting providers to disclose patient information when harm is merely “foreseeable,” given the well-documented challenges of predicting risk.³⁵

Additionally, while the Department does not explicitly contemplate changing the provisions of the Privacy Rule that permit certain disclosures of information related to child maltreatment,³⁶ its proposal may nevertheless open the door for greater government interference in parent-child and family relationships without adequate justification. The consequences for children and families would be dire—mirroring the harms of the criminal legal system³⁷—and the Department must take account of them before it considers weakening the Privacy Rule.

³⁰ Am. Hosp. Ass’n, *Black, Indigenous and People of Color Mental Health*, <https://www.aha.org/bipoc-mental-health>.

³¹ Lonnie R. Snowden, Julia F. Hastings, & Jennifer Alvarez, *Overrepresentation of Black Americans in Psychiatric Inpatient Care*, 60 *Psychiatric Servs.* 779 (Jun. 2009), available at <https://ps.psychiatryonline.org/doi/pdf/10.1176/ps.2009.60.6.779>.

³² See, e.g., Compl. for Decl. & Inj. Relief, *Disability Rights California v. Cnty. of Alameda*, No. 3:20-cv-05256-CRB (N.D. Cal. Jul. 30, 2017), ECF No. 1.

³³ See *Olmstead v. L.C.*, 527 U.S. 581, 583 (1999) (“[I]nstitutional placement of persons who can handle and benefit from community settings perpetuates unwanted assumptions that persons so isolated are unworthy of participating in community life.”)

³⁴ 86 Fed. Reg. 6483.

³⁵ *Supra* note 14.

³⁶ See 45 C.F.R. §§ 164.512(b)(1)(ii), 164.512(c)(1). The Department does not suggest changes to either of these provisions, but does request comment on whether it should consider weakening the reporting standard under § 164.512(c)(1) of the Privacy Rule. See discussion *infra*.

³⁷ See, e.g., Sara Wakeman, Ayana Jordan, & Leo Beletsky, *When Reimagining Systems of Safety, Take a Closer Look at the Child Welfare System*, *Health Affairs* (Oct. 7, 2020), 10.1377/hblog20201002.72121; Dorothy Roberts & Lisa Sangoi, *Black Families Matter: How the Child Welfare System Punishes Poor Families of Color*, *The Appeal* (Mar. 26, 2018), <https://theappeal.org/black-families-matter-how-the-child-welfare-system-punishes-poor-families-of-color-33ad20e2882e/>.



Providers making disclosures under the emergency disclosure provision, 45 C.F.R. § 164.512(j)(1)(i), may count child protective workers—or law enforcement agencies who will themselves transmit information to child protective workers—among those “persons reasonably able to prevent or lessen [a] threat.”³⁸ Because family regulation agencies that receive reports of possible harm are incentivized to err on the side of separating families even when in doubt about the necessity of removing children from their parents, increased reports to those agencies are likely to increase the rates of family separation.³⁹ Moreover, even where calls to child protective services do not result in child removal, the increased surveillance of a family that comes with even “light touch” child welfare responses infringes on parents’ fundamental liberty interest in the care and custody of their children and on the parent-child relationship. Studies and first-person accounts describe the fear, anxiety, and distrust—both within the family and with respect to state actors—that results from being under a caseworker’s scrutiny.⁴⁰ The majority of reports to child protection services across the country, including those by mandatory reporters like healthcare service providers, do not result in findings of abuse,⁴¹ but nevertheless can create a record of contact with the child protective agency that will have adverse consequences for employment or the ability to maintain custody of one’s children in the

³⁸ 45 C.F.R. § 164.512(j)(1)(i)(B).

³⁹ See, generally, Dorothy Roberts, *Shattered Bonds: The Color of Child Welfare* (2002).

⁴⁰ See, e.g., Kelley Fong, *Getting Eyes in the Home: Child Protective Services Investigations and State Surveillance of Family Life*, 85 *Am. Sociological Rev.* 610 (Aug. 1, 2020), available at <https://doi.org/10.1177/0003122420938460>; Rachel Blustain and Nora McCarthy, *The Harmful Effects of New York City’s Over-Surveillance*, The Imprint (Oct. 21, 2019), <https://imprintnews.org/child-welfare-2/the-harmful-effects-of-over-surveillance/38441>; Kendra Hurley, *When Child Welfare Cases Police Women in Their Homes*, Bloomberg (Jun. 11, 2020), <https://www.bloomberg.com/news/articles/2020-06-11/how-child-welfare-cases-surveil-parents-of-color>.

⁴¹ According to the latest data collected and released by the federal government, in 45 states, 45.5% of complaints to child abuse hotlines are dismissed outright with no agency action. U.S. Dep’t of Health & Human Servs, Amin. for Children & Families, Children’s Bureau, *Child Maltreatment 2019* (2019), available at <https://www.acf.hhs.gov/sites/default/files/documents/cb/cm2019.pdf> (“Among the 45 states that report both screened-in and screened-out referrals, 54.5 percent of referrals are screened in and 45.5 percent are screened out.”). Of those complaints that were investigated, and where agencies found allegations to be substantiated, “74.9 percent of victims are neglected, 17.5 percent are physically abused, and 9.3 percent are sexually abused.” *Id.*



future.⁴² The proposed changes to 45 C.F.R. 164.512(j)(1)(i)(A) incentivize disclosures to family regulation system authorities in situations that would not prompt such calls under the existing rules, suggesting that agencies will be faced with a larger number of complaints but not ones that are more likely to capture incidents that justify government intrusion into the family, let alone family separation. And like the criminal legal system, the burdens of these removals fall disproportionately on Black, indigenous, and other families of color, and poor families.⁴³

Those harms may also be triggered by other changes proposed in the Notice. First, third parties not covered under HIPAA—with whom the Notice proposes sharing information more freely in several circumstances, some unrelated to emergencies⁴⁴—may include mandated reporters or other individuals likely to call in suspicions of neglect. For example, the Notice proposes to add to 45 C.F.R. § 164.501 an “express permission” allowing covered entities to share patient information with social services agencies, community-based organizations, and home-based care services providers to facilitate health-related services.⁴⁵ Thus, a food pantry or housing shelter worker with access to new streams of protected patient health information could be incentivized to report parents who they know are receiving substance use or mental health treatment, including against a provider’s better judgment. Poor families who disproportionately rely on such services⁴⁶ would be chilled from accessing them to their full

⁴² Colleen Henry, et al., *The Collateral Consequences of State Central Registries: Child Protection and Barriers to Employment for Low-Income Women and Women of Color*, 64 Soc. Work 373 (Jul. 2019), available at <https://doi.org/10.1093/sw/swz025>; Tex. Pub. Pol. Found., *The BlackList: How Central Registry Reform Can Protect Kids and Promote Prosperity* (May 2020), available at <https://files.texaspolicy.com/uploads/2020/05/28093855/Huntzinger-Central-Registry.pdf>.

⁴³ See Roberts, *supra* note 39; Nat’l Conf. of State Legislatures, *Disproportionality and Race Equity in Child Welfare* (Jan. 26, 2021), <https://www.ncsl.org/research/human-services/disproportionality-and-race-equity-in-child-welfare.aspx#Numbers>; Children’s Bureau, *Racial Disproportionality and Disparity in Child Welfare* (Nov. 2016), https://ncwwi.org/files/Cultural_Responsiveness__Disproportionality/Racial_Disproportionality_and_Disparity_in_Child_Welfare.pdf.

⁴⁴ 86 Fed. Reg. 6476 (“[I]n general, the third party [providers of social services] receiving PHI under this proposed permission would not be covered entities and thus, the PHI disclosed to them would no longer be protected.”).

⁴⁵ *Id.*

⁴⁶ Emily Putnam-Hornstein & Barbara Needell, *Predictors of Child Protective Service Contact Between Birth and Age Five: An Examination of California’s*



benefit.⁴⁷ Another proposal would weaken the standard under which providers could share the protected information of individuals living with substance use disorder or serious mental illness with those individuals' family members and caregivers in certain situations.⁴⁸ In a similar vein to the above, a well-meaning family member who was notified of their loved one's overdose under one of the proposed modifications to 45 C.F.R. § 164.510(b) might contact the local department of social services to seek support. Such a call would almost certainly trigger an invasive child protective investigation and other interventions not geared toward treatment.⁴⁹ The Department should avoid widening the net of mandated reporters and other third parties with access to protected information.

Second, the Department also requests comment on whether it should modify the Privacy Rule to facilitate greater disclosures pursuant to 45 C.F.R. § 164.512(c), which concerns disclosures "about victims of abuse, neglect, or domestic violence," by replacing the current "professional judgment" standard with a more nebulous one based on "good faith belief."⁵⁰ It should not. Such a change would extend an open invitation to covered entities to make biased reports, entrenching the family regulation system's class and racial harms.⁵¹ Furthermore, as the Department correctly recognizes, unlinking the standard for reports of child neglect from provider's expertise would not respond to any identifiable need.⁵² Instead, the Department should

2002 Birth Cohort, 338 *Children & Youth Servs. Rev.* 1337 (2011), available at <https://doi.org/10.1016/j.chilyouth.2011.04.006>.

⁴⁷ Kelley Fong, *Concealment and Constraint: Child Protective Services Fears and Poor Mothers' Institutional Engagement*, 97 *Social Forces* 1785 (Oct. 1, 2018), available at <https://doi.org/10.1093/sf/soy093>.

⁴⁸ *Supra* note 19.

⁴⁹ Movement for Family Power, "Whatever They Do, I'm Her Comfort, I'm Her Protector:" *How the Foster System Has Become Ground Zero for the U.S. Drug War* (Jun. 2020), available at <https://www.movementforfamilypower.org/ground-zero>.

⁵⁰ 86 Fed. Reg. 6525.

⁵¹ Emily Putnam-Hornstein, et al., *Cumulative Rates of Child Protection Involvement and Terminations of Parental Rights in a California Birth Cohort, 1999-2017*, 111 *Am. J. of Pub. Health* 1157 (Jun. 2021), available at <https://doi.org/10.2105/AJPH.2021.306214>; Dorothy Roberts, *The Child Welfare System's Racial Harm*, 44 *Nomos* 98 (2003), available at <https://www.jstor.org/stable/24220072?seq=1>.

⁵² 86 Fed. Reg. 6524 ("the Department believes [the provisions contained in 45 C.F.R. 512(c)] are well suited to ensuring that the necessary reporting can occur, and it does not believe replacing the professional judgment standard would . . . prevent a course of action related to an individual affected by the

let the current rule stand, and encourage covered entities to take seriously the harm that family separation and surveillance cause to children and parents alike.⁵³

C. *Weakening Patient Privacy Protections Would Chill Patient Engagement and Diminish Access to Care.*

The right to medical privacy is essential to an individual's trust in and relationship with their health care providers, and their commitment to treatment. Weakening individual medical privacy protections would chill treatment, contrary to the Department's stated purposes. The Department should therefore forego any changes to the Privacy Rule that would diminish patients' decision-making autonomy and trust by facilitating increased disclosures of their PHI whether to social service providers, law enforcement entities, family members, or other third parties, either in emergency circumstances or to facilitate treatment.



This is again particularly true for people with mental health disabilities, substance use disorders, and other conditions, treatments, histories, and statuses that are associated with social stigma and discrimination. For myriad reasons, an individual who is participating in treatment may not want private protected information disclosed to other health care providers or social service providers, or to involved friends and family members. For example, disclosing information about a mental health condition or substance use disorder, or information that was shared in confidence during the course of treating that condition or disorder, with a family member without the person's consent, may in some circumstances damage important relationships and hinder treatment. People with disabilities who have their PHI improperly shared risk experiencing disability-based discrimination in other critical components of their lives, including employment, housing, and education. People with mental health

opioid crisis."); see also David Carry, *HHS Leaders: No Evidence of Child Abuse Surge Amid Pandemic* (Jan. 14, 2021), <https://apnews.com/article/us-news-health-coronavirus-pandemic-child-welfare-child-abuse-2c88d66ab57e1b621cf86d3657536ce7> (even where reporting rates significantly diminished, no reason to believe reporting was insufficient).

⁵³ See, e.g., Eli Hager, *The Hidden Trauma of 'Short Stays' in Foster Care*, The Marshall Proj. (Feb. 11, 2020), available at <https://www.themarshallproject.org/2020/02/11/the-hidden-trauma-of-short-stays-in-foster-care>; Stephanie Clifford and Jessica Silver-Green, *Foster Care as Punishment: The New Reality of 'Jane Crow'*, N.Y. Times (July 21, 2017), available at <https://www.nytimes.com/2017/07/21/nyregion/foster-care-nyc-jane-crow.html>.



disabilities who have their psychiatric diagnosis shared with others are at particular risk of having incorrect presumptions made about their capacity to make medical decisions and to live independently. The Department therefore assumes too much when it asserts that a weaker privacy regime would positively impact treatment of mental health disabilities and substance use disorders by increasing social supports.⁵⁴ A patient who fears their confidences will be breached is just as likely to forego or disengage from treatment.⁵⁵ Tellingly, the Department acknowledges this in its Notice and writes that:

Commenters who identified as patients . . . almost universally opposed modifying the Privacy Rule to expand permitted disclosures. Many commenters expressed fear of family members and employers having access to this information, citing potentially adverse consequences, including fear of discrimination, abuse, and retaliation. Many health care providers expressed concern about the chilling effect that increased disclosures would have on individuals seeking treatment for opioid use disorders and stated that the Privacy Rule is flexible enough.⁵⁶

Given the paucity of evidence HHS offers in support of a weakened Privacy Rule, it remains unclear why the Department has opted to overlook patients' and providers' overwhelming support for the current, adequately protective framework.⁵⁷ It is well established that individuals who are no longer certain that their information is protected are often deterred from accessing or continuing treatment, or omit important information in the course of treatment in order to protect their privacy.⁵⁸ Instead of undermining the interests of patients and health care providers, the Department should heed their fears of adverse consequences and chilling effect, especially considering the

⁵⁴ 86 Fed. Reg. 6501–02.

⁵⁵ See, e.g., Pamela Sankar, *Patient Perspectives of Medical Confidentiality*, 18 J. Gen. Internal Med. 659 (2003) (finding that patients who distrusted confidentiality protections would delay or forego medical care).

⁵⁶ 85 Fed. Reg. 6480.

⁵⁷ Cf. *Motor Veh. Mfrs. Ass'n*, 463 U.S. at 43.

⁵⁸ See, e.g., Janlori Goldman and Zoe Hudson, Georgetown University Health Privacy Project, *Promoting Health/Protecting Privacy: A Primer* (Jan. 1999), available at <https://www.chcf.org/wp-content/uploads/2017/12/PDF-conprimer.pdf>.

possibility that increased disclosures would reach law enforcement and prejudice vulnerable patients.⁵⁹

II. Congress Considered and Rejected Privacy Rules that Would Be Less Protective of Individuals Based on Diagnosis

As outlined above, the Department’s proposed modifications to the Privacy Rule would effectively leave patients with certain mental health diagnoses less protected than others against non-consensual disclosures of confidential health information. HHS lacks authority to promulgate regulations that would have this result, including the provisions discussed in this Letter. Congress did not authorize differential privacy protections based on diagnosis when it enacted HIPAA. Moreover, Congress rightly rejected legislative efforts to lower privacy protections for individuals with serious mental illness.

Early versions of the Helping Families in Mental Health Crisis Act, which passed as part of the 21st Century Cures Act,⁶⁰ would have reduced privacy protections for individuals with serious mental illness by broadening the circumstances under which health information could be disclosed to such individuals’ caregivers.⁶¹ Congress declined to adopt the provisions weakening the privacy rights of individuals with serious mental illness, however, and indicated that communication problems between providers and caregivers for people with serious mental illness reflect “confusion in the health care community” concerning permitted disclosures and uses under HIPAA.⁶² Congress directed HHS OCR to “ensure that health care providers, professionals, patients and their families, and others involved in mental or substance use disorder treatment have adequate, accessible, and easily comprehensible resources relating to appropriate uses and disclosures of protected health information” under HIPAA, and to issue guidance clarifying permitted uses or disclosures of PHI for purposes of communicating with family members or others who are involved in a

⁵⁹ The Supreme Court has on several occasions recognized that facilitating law enforcement access to patients’ medical health information “may have adverse consequences because it may deter patients from receiving care.” *Ferguson v. City of Charleston*, 532 U.S. 67, 78 n.14 (2001) (citing *Whalen v. Roe*, 429 U.S. 589, 599–600 (1977)).

⁶⁰ 21st Century Cures Act, Pub. L. No. 114–255, § 11001(a)(9), codified at 42 U.S.C. § 201.

⁶¹ *See, e.g.*, H.R. 2646, Title IV: HIPAA and FERPA Caregivers (114th Congress).

⁶² *See supra* note 60.



patient’s care, law enforcement agents, and others, to coordinate care and respond to emergencies.⁶³

HHS did promulgate guidance addressing those issues, as well as guidance addressing similar issues for individuals with substance use disorders, to clarify what uses and disclosures are permitted.⁶⁴ In soliciting these materials from OCR, Congress was clear that they should be geared toward clarifying “*existing* permitted uses and disclosures,” rather than promulgating less protective standards under modified rules.⁶⁵ To the extent the Department remains concerned about confusion on this point, its efforts would be best spent disseminating information and training to educate providers, family members, and individuals with serious mental illness and/or substance use disorders about what HIPAA requires, rather than trying to modify HIPAA regulations in a manner that defies Congressional intent.



* * *

Encouraging providers to more liberally share individuals’ private protected medical information beyond the existing rules is unsupported and would cause predictable harms. The Department largely ignores these critical problems in its Notice. The Department should instead focus its efforts on strengthening or maintaining the HIPAA Privacy Rule’s existing protections. If you have any questions, please contact Kate Ruane at KRuane@aclu.org.

⁶³ *Id.* § 11003.

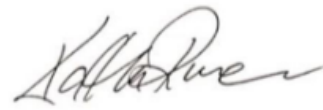
⁶⁴ U.S. Dep’t of Health & Human Servs., *HIPAA Privacy Rule and Sharing Information Related to Mental Health*, available at <https://www.hhs.gov/sites/default/files/hipaa-privacy-rule-and-sharing-info-related-to-mental-health.pdf>; see also U.S. Dep’t of Health & Human Servs., *Information Related to Mental and Behavioral Health, Including Opioid Overdose*, <https://www.hhs.gov/hipaa/for-individuals/mental-health/index.html>.

⁶⁵ See, e.g., 21st Century Cures Act, Pub. L. No. 114–255, § 11001(b), codified at 42 U.S.C. § 201 (emphasis added).

Respectfully,



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