



**CONSORTIUM FOR CITIZENS  
WITH DISABILITIES**

May 6, 2021

*Submitted Via Federal eRulemaking Portal at [www.regulations.gov](http://www.regulations.gov)*

Robinsue Frohboese  
Acting Director  
Office for Civil Rights  
U.S. Department of Health and Human Service  
Hubert H. Humphrey Building, Room 509F  
200 Independence Avenue SW  
Washington, DC 20201

RE: Department of Health and Human Services, Office for Civil Rights RIN  
0945-AA00, Docket No. OCR-OCR-0945-AA00

Dear Acting Director Frohboese:

The undersigned members and allies of the Consortium for Citizens with Disabilities (CCD) Rights and Health Task Forces submit these comments in response to the Proposed Modifications to the HIPAA Privacy Rule to Support, and Remove Barriers to, Coordinated Care and Individual Engagement by the Department of Health and Human Services (HHS) and Office of Civil Rights (OCR). CCD is the largest coalition of national organizations working together to advocate for Federal public policy that ensures the self-determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society.

We strongly oppose key provisions of this proposal that would weaken the HIPAA Privacy Rule and we urge OCR not to adopt those provisions in a final rule. The proposed changes to which we object are OCR's proposals to: (1) eliminate the requirement that professional judgment be exercised in determining whether disclosure is warranted without an individual's consent under five exceptions to privacy protections, (2) add a presumption under these exceptions that any use or disclosure of protected health information was done in "good faith," (3) remove the requirement that harm must be serious and imminent under the "dangerousness" exception, (4) add a presumption to the dangerousness exception that the harm was sufficient to warrant use or disclosure of protected health information, (5) add a requirement that heightened deference be given to the decisions of mental or behavioral health professionals or other providers with "specialized training, expertise, or experience in assessing an individual's risk to health or safety" to invoke the dangerousness exception, and (6) remove the "minimum necessary"

standard for disclosures for individual-level care coordination and case management as well as broadening the allowance of disclosures to third parties.

The proposed changes are beyond OCR's authority to promulgate because they are not grounded in specific evidence as required by the Administrative Procedures Act but merely in generalized assumptions and speculation. Moreover, they would cause significant harm to individuals with disabilities and others who wish to keep sensitive health information private. The proposed rule would destroy the careful balance struck by the current HIPAA Privacy Rule that enables individuals to seek needed services without fear that their health information will be disclosed to others without their consent; it would deter individuals from seeking needed services and expose individuals to harm by allowing disclosure over their objection to individuals who may use that information to perpetrate abuse or harm. Finally, the proposed changes ignore that Congress considered and rejected similar measures to reduce privacy rights and expand disclosure to family members and caregivers over individuals' objection in the 21<sup>st</sup> Century Cures Act; Congress opted instead to require OCR to provide more clarity to stakeholders rather than changing privacy protections.

We also note that the proposed rule, while it claims not "to imply that individuals with mental or behavioral health conditions are more likely than other individuals to commit acts of violence" or "to perpetuate false and harmful stereotypes about individuals with SMI [serious mental illness] or SUD [substance use disorder]," does precisely that. The repeated suggestions that these individuals' protected health information should be disclosed in order to prevent mass violence are unfounded and frankly shocking. The HIPAA Privacy Rule already has exceptions that allow for disclosure where necessary to avert a serious and imminent threat. Yet the proposed rule suggests, without evidence, that even without such a threat individuals' health information (apart from any actual *conduct*), is somehow predictive of mass violence. This is [simply wrong](#) and the same stereotypes and prejudices behind these suggestions pervade much of the discussion of why OCR believes the HIPAA Privacy Rule protections must be weakened and disclosures of individuals' health information against their will expanded.

The proposed rule also reflects a cavalier attitude concerning the potential harms that would be done by removing individuals' privacy protections. For example, OCR notes that it "understands that these proposals may raise concerns about unintended consequences where a covered health care provider is asked to disclose sensitive information to family members or other caregivers about individuals at risk of, or experiencing, abuse by the requesting family members or caregivers"<sup>1</sup>—but swiftly dismisses these concerns on the ground that providers can consider the potential for abuse in deciding whether to disclose and would simply not disclose in any situation where disclosure is not in an individual's best interest, even if the provider is no longer expected to exercise any type of professional judgment.<sup>2</sup> Further, OCR does not even mention the possibility that a provider might not be aware of abuse that is occurring or the potential for abuse.

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<sup>1</sup> Proposed Modifications to the HIPAA Privacy Rule to Support, and Remove Barriers to, Coordinated Care and Individual Engagement, 83 Fed. Reg. 6472, 6481 (Jan. 21, 2021).

<sup>2</sup> *Id.*

1. **OCR Has No Authority Under the Administrative Procedures Act to Promulgate the Provisions Expanding Exceptions to Privacy Protections and Removing the “Minimum Necessary” Standard for Disclosures for Care Coordination and Case Management.**

OCR lacks authority under the Administrative Procedures Act (APA) to promulgate the proposed changes outlined above to weaken privacy protections and expand disclosure of protected health information without consent. The APA requires that regulations must be based on *actual evidence* that a proposed rule is necessary to address a particular problem, and not merely on speculation. The agency promulgating a rule must “examine the relevant data and articulate a . . . rational connection between the facts found and the choice made.” *Motor Veh. Mfrs. Ass'n v. State Farm Ins.*, 463 U.S. 29, 43 (1983) (citing *Burlington Truck Lines, Inc. v. United States*, 371 U.S. 156, 168 (1962)).

The proposed rule fails to meet that standard. It provides no evidence of instances where the Privacy Rule’s application proved specifically problematic, much less evidence that the proposed changes will solve the purported problems. The proposed rule relies almost exclusively on generalized statements from commenters, without the type of evidence or data that agencies routinely rely on in adopting or changing a rule. For example, OCR proposes eliminating the requirement that providers exercise professional judgment in determining whether certain exceptions to privacy protections apply based on “evidence” such as:

“Despite issuing extensive guidance, OCR continues to hear that some covered entities are reluctant to disclose information to persons involved in the care of individuals experiencing [mental and behavioral health] issues, even when the Privacy Rule permits such disclosures.”

“The Department has similarly heard anecdotal accounts that some health care providers are reluctant to disclose needed health information about an incapacitated patient to even their closest friends and family, due to concerns about potential penalties under HIPAA. OCR understands that this reluctance to disclose, even when the Privacy Rule permits disclosure, creates particular difficulties, and potential risks for patients and others, when a patient is unable to agree or object to the disclosure due to incapacity related to SMI, SUD, or another cause.”

“In addition, 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, even when such disclosure could prevent or lessen a serious and imminent threat of harm or violence. According to these accounts, the reluctance to disclose persists even though the HIPAA Rules permit disclosure in such circumstances.”<sup>3</sup>

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<sup>3</sup> *Id.* at 6479. OCR offers one additional example, highlighting the testimony of a single individual on a panel of witnesses who testified before the Federal School Safety Commission on privacy issues that “providers continue to “stonewall” families when asked to disclose PHI and routinely withhold medical information from family members, out of concerns of potentially violating HIPAA.” *Id.* and note 210. Yet OCR fails to mention that every person on that panel, including one of the signatories to this letter, testified that the HIPAA Privacy Rule was not the problem and to the extent that stakeholders were in fact misinterpreting HIPAA, more education, training and guidance was needed.

First, such vague and generalized statements devoid of any specific facts do not form an appropriate basis for making major changes to weaken protections in a longstanding rule. Second, each of these statements acknowledges that the current Privacy Rule *does* allow the disclosures to occur—the Privacy Rule is not the cause of the purported problems. Yet the proposed rule does not address why, if the Privacy Rule would in fact allow these disclosures, it must be changed and weakened.<sup>4</sup> Third, OCR seems to assume that disclosure should always be the right outcome and fails to consider whether providers choose not to disclose in many of these instances, even where permitted by HIPAA, because disclosure would do more harm than good or not be in a person’s best interests.

Moreover, many of the generalized statements relied on by OCR do not even claim that the Privacy Rule *actually* limits disclosure or use of protected health information in problematic ways. Instead, they contend that the problem is *uncertainty* about how the Rule should be applied. For example:

“ . . . some covered entities expressed *uncertainty* regarding whether the use or disclosure of PHI for a particular care coordination or case management activity is permitted as part of treatment, health care operations, both, or neither.”<sup>5</sup>

“Some covered entities reported that, due to *uncertainty* about which provisions apply in certain circumstances, they do not request or disclose PHI even when doing so would support coordinated care and the transformation of the health care system to value based care.”<sup>6</sup>

“Some commenters reported that this *uncertainty* about compliance requirements creates *fears* that may result in less information sharing, and therefore less efficient and effective care.”<sup>7</sup>

“The proposal would also remove the disincentive to disclose and request PHI to support care coordination and case management based on *uncertainty* about applicable permissions and *fear* of being subject to penalties for noncompliance resulting from such *uncertainty*.”<sup>8</sup>

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<sup>4</sup> Even if the comments had suggested that the Privacy Rule did not allow disclosure and should be changed, without any discussion of the factual basis for these comments, it is impossible to discern whether they would even be valid. Many complaints about the HIPAA Privacy Rule that have been made over the years have been based on fundamental misunderstandings about the Rule. For example, Congressional hearings convened by former Representative Tim Murphy (R-PA) with an aim of showing that HIPAA provided too many privacy protections to individuals with psychiatric disabilities featured multiple witnesses who blamed HIPAA for providers’ decisions not to disclose health information to family members when in fact HIPAA posed no bar to disclosure. For example, one witness blamed HIPAA for a hospital’s refusal to provide him with information about his son, but testified that the son had signed a release permitting the hospital to disclose information to his parents. Another witness claimed that HIPAA barred her from providing any information to family members of an individual lying unconscious on an emergency room bed, even though multiple provisions of the Privacy Rule would have allowed disclosure.

<sup>5</sup> *Id.* at 6472.

<sup>6</sup> *Id.*

<sup>7</sup> *Id.* at 6473.

<sup>8</sup> *Id.* at 6474.

“*Uncertainty* about how to apply the minimum necessary standard creates *fears* of HIPAA enforcement action among covered entities that could inhibit information sharing, and may result in less efficient and effective care.”<sup>9</sup>

These comments may highlight reasons to *clarify* the Privacy Rule, but they do not constitute a basis for *changing its standards*. OCR has issued multiple guidance documents clarifying a myriad of applications of the Rule, but if it believes that there is still uncertainty about what the Rule requires, it is free to issue additional guidance to clarify those requirements. It is *not* free to change the Rule on that basis.

In the absence of a factual basis to support its proposals, OCR has not met the standard required by the APA for rulemaking.

## **2. The Proposed Rule Poses Particular Harms for Individuals with Disabilities**

We strongly oppose the following changes that OCR proposes making to the HIPAA Privacy Rule to weaken privacy protections and expand permitted disclosures. These changes are unnecessary, unwarranted, and would harm individuals by interfering with the effectiveness of treatment, deterring individuals from seeking treatment, and in some cases making individuals more vulnerable to abuse or mistreatment. They are:

- **Replacing “professional judgment” with “a good faith belief.”** OCR proposes to weaken the standard for disclosure of protected health information to remove the requirement that covered entities exercise “professional judgment” in determining whether any of five exceptions to privacy protections apply (including, for example, disclosure to a parent or guardian who is not the person’s personal representative when in the person’s best interest, and disclosure in an emergency or when the person lacks the capacity to object). Instead of professional judgment, covered entities must merely have a “good faith belief” that use or disclosure is in the person’s best interest.
- **Presuming that a good faith belief always exists.** In addition to weakening the standard to require only a “good faith belief,” OCR also proposes a presumption that such “good faith belief” exists any time a person’s protected health information is used or disclosed under these exceptions. Under OCR’s proposal, not only would individuals lose the protection and accountability that the “professional judgment” standard afforded, but the invocation of these exceptions would be largely unreviewable. Individuals would be effectively left with no recourse for significant violations of their privacy rights, and no confidence that they had privacy protections.
- **Replacing the requirement of a “serious and imminent threat” with “serious and reasonably foreseeable harm.”** OCR proposes to remove the requirement of a “serious and imminent threat” to health or safety to justify the disclosure of a person’s protected

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<sup>9</sup> *Id.* at 6493.

health information without consent. Instead, OCR would merely require a threat or harm that is “serious and reasonably foreseeable,” using a reasonable person standard.

- **Presuming that the harm is always “reasonably foreseeable.”** In addition, OCR would add a presumption that harm was “reasonably foreseeable” whenever this exception is invoked to justify using or disclosing a person’s protected health information without consent. Because of the already existing presumption that use or disclosure of protected health information was done in good faith under this exception, OCR notes that with the proposed changes, “a covered entity that reports a threat to health or safety could potentially benefit from two presumptions:” a presumption that the harm identified was reasonably foreseeable *and* a presumption that the covered entity believed the disclosure or use was necessary to prevent harm or lessen a threat. These presumptions would make the invocation of this exception effectively unreviewable.
- **Heightened deference to mental health professionals invoking the dangerousness exception.** Further, OCR would afford heightened deference to the decisions of mental or behavioral health professionals or other providers with “specialized training, expertise, or experience in assessing an individual’s risk to health or safety” to invoke the dangerousness exception. OCR also inquires whether it should go *even further* and *automatically allow* all disclosures by mental and behavioral health professionals who believe disclosure “*could* prevent serious and reasonably foreseeable harm or lessen a serious and reasonably foreseeable threat” to health or safety.
- **Removing the “minimum necessary” requirement for care coordination and case management.** OCR proposes to remove the requirement that disclosures for individual-level care coordination and case management be limited to information that is the “minimum necessary.”

These changes would destroy important privacy protections relied on by all individuals who use health services, guaranteeing that many would decline to seek needed treatment and/or choose not to reveal important information due to concerns about the lack of privacy protection, making services less effective. In addition, the proposed changes would leave individuals vulnerable to abuse—particularly victims of domestic violence seeking mental health treatment, LGBTQ or non-binary individuals seeking mental health treatment to address difficulties with family members who do not accept their sexual orientation or gender identity or individuals seeking hormone therapy or gender reassignment surgery despite objections of family members, and individuals seeking substance use disorder treatment who are concerned about exposure to criminal charges if information is revealed to family members.

Instead of weakening the disclosure standards, OCR should focus on educating covered entities and other stakeholders concerning when protected health information may be disclosed or used. For example, HHS should consult with experts and “develop a frequently updated decision tool to inform best practices on optimal workforce training related to the importance of privacy,

security, the professional treatment of patients, and professionals.”<sup>10</sup> Training is an appropriate solution to the concerns raised by OCR. Changing the standard is not.

**a. *Eliminating Professional Judgment and Presuming a Good Faith Belief to Invoke Exceptions to Privacy Protections Would Harm Individuals Seeking or Receiving Health Services***

The requirement that covered entities use professional judgment in determining whether exceptions to Privacy Rule protections exist is a bare minimum protection to ensure some measure of accountability in how the exceptions are determined. HIPAA’s privacy protections are critical to ensure that individuals can freely provide information that may be important to their treatment without fear that such information will be disclosed without their consent to others. For people with disabilities, the unwanted disclosure of their private health information poses particular concerns by opening the door to disability-based discrimination in many aspects of their lives.

The proposal to add a presumption that all decisions made by a covered entity concerning disclosure under these exceptions are made based on a good faith belief adds insult to injury. In combination, the replacement of the requirement of professional judgment with a “good faith belief” and the presumption that a “good faith belief” always exists would make HIPAA’s privacy protections largely a nullity. In effect, the proposal conveys to covered entities that they may do as they please with individuals’ protected health information. The entire purpose of the Privacy Rule would be gutted if OCR adopted these proposed changes.

In its Request for Comments, OCR seeks public input on whether changing the standard from “professional judgment” to “good faith belief” would discourage individuals from seeking care. The answer is unquestionably “yes.” A national survey indicated that 68% of respondents were “somewhat” or “very concerned” about the privacy and security of their medical records.<sup>11</sup> Another recent study indicates that patients who were concerned about their electronic medical information being compromised were three times more likely than patients without concerns to withhold information from their provider.<sup>12</sup> Expanding disclosure of individuals’ private health information without their consent often leads to a “profound sense of anxiety” and “‘privacy-protected’ behaviors.”<sup>13</sup> Individuals concerned about unwanted disclosure of their health information engage in privacy-protective behaviors meant to “avoid embarrassment, stigma, and discrimination,” include omitting information during treatment, avoiding health care, and frequently switching doctors to avoid a single provider accessing their full medical record.<sup>14</sup> This

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<sup>10</sup> Julie L. Agris & John M. Spandorfer, *HIPAA Compliance and Training: A Perfect Storm for Professionalism Education?* 44 J. L., MED. & ETHICS 652, 655 (2016).

<sup>11</sup> Consumers and Health Information Technology A National Survey, California HealthCare Foundation (April 2010), <https://www.chcf.org/wp-content/uploads/2017/12/PDF-ConsumersHealthInfoTechnologyNationalSurvey.pdf>.

<sup>12</sup> Matthew J. DePuccio et al., *Patients’ Perceptions About Medical Record Privacy and Security: Implications for Withholding of Information During the COVID-10 Pandemic*. 35 J. GEN. INTERNAL MED. 3122, 3122 (2020).

<sup>13</sup> Janlori Goldman and Zoe Hudson, *Promoting Health/Protecting Privacy: A Primer*, Georgetown University Health Privacy Project (Jan. 1999), <https://www.chcf.org/wp-content/uploads/2017/12/PDF-conprimer.pdf>.

<sup>14</sup> *Id.*

interferes with health care providers' ability to accurately diagnose and treat individuals and lowers quality of care.

Additionally, OCR seeks Request for Comments on whether OCR should apply the good faith standard to *all* of the exceptions that currently require the exercise of professional judgment. It should not apply this standard to *any* of these exceptions. Everyone deserves to have non-consensual disclosure of their personal health information evaluated based on professional judgment. Substituting "good faith belief" for professional judgment is highly problematic for reasons described above and disrespects basic human dignity.

**b. *Modifying the "Serious and Imminent Threat" Standard to "Reasonably Foreseeable Threat" Would Deter People from Seeking Needed Services***

OCR proposes to amend the Privacy Rule to change the current language permitting disclosures to avert a "serious and imminent" threat to health or safety to when a harm is "serious and reasonably foreseeable." However, this proposal would cause serious harm. Instead of genuinely focusing on a threat to safety, covered entities would have virtually unfettered discretion to disclose protected health information under the dangerousness exception. Further, far too frequently, health providers have incorrectly assumed that individuals with disabilities, and particularly psychiatric or intellectual disabilities or autism, have poor judgment or what is often dubbed "lack of insight" and are likely to engage in risky behavior. Under OCR's proposal, any determination that serious harm is "reasonably foreseeable" would be presumed accurate.

This proposal would deter individuals from engaging with service providers. If the standard to use and disclose their protected health information is so low and so broad, individuals would be rightly concerned that any behavior or comment could be grounds for disclosure. As observed in one study, "a significant minority of patients distrust confidentiality protections, leading some to report that they delay or forgo medical care."<sup>15</sup> The study found that "[i]f doubtful that confidentiality will be upheld, patients will act independently to protect information."<sup>16</sup> Regarding treatment, "mental health patients all reported at least occasional instances when they chose not to seek treatment because of confidentiality concerns, or decided to withhold information during clinical interactions for the same reason."<sup>17</sup> Reducing confidentiality and privacy makes it more likely that many individuals will decline to seek needed services.

Additionally, OCR's proposal to afford "heightened deference" to mental health or substance use disorder professionals on the theory that they have specialized expertise in assessing risk such as violence or suicide risk is misguided.<sup>18</sup> While OCR states it does not intend this proposal to "perpetuate false and harmful stereotypes about individuals with SMI or SUD,"<sup>19</sup> singling out these individuals for lower privacy protection does just that. OCR states that it "does not mean to

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<sup>15</sup> Pamela Sankar, *Patient Perspectives of Medical Confidentiality*, 18 J. GEN. INTERNAL MED. 659, 659 (2003).

<sup>16</sup> *Id.*

<sup>17</sup> *Id.* at 666.

<sup>18</sup> Proposed Modifications to the HIPAA Privacy Rule, at 6533.

<sup>19</sup> *Id.* at 6483.



imply that individuals with mental or behavioral health conditions are more likely than other individuals to commit acts of violence.”<sup>20</sup> Yet this is exactly what OCR implies.

OCR’s inquiry about whether it should go even further and automatically allow any disclosures by “mental and behavioral health professionals who believe that a disclosure “*could* prevent serious and reasonably foreseeable harm or lessen a serious and reasonably foreseeable threat” to health or safety is even more troubling. First, there is no basis for OCR’s assumption that mental health professionals have special expertise that makes them particularly good at predicting risk. To the contrary, these professionals have had no more success than others at predicting risk. Studies have consistently shown that mental health professionals do not have tools to predict risk, danger, or suicide with any accuracy. For example, the lead author of a widely read meta-analysis of the last fifty years of research on assessing suicide risk stated:

*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 prediction.*<sup>21</sup>

The same is true of assessment of risk and dangerousness generally. The abstract of a 2019 review of research on risk assessment in the context of sentencing states:

*Predictions of dangerousness are more often wrong than right, use information they shouldn’t, and disproportionately damage minority offenders. Forty years ago, two-thirds of people predicted to be violent were not. For every two “true positives,” there were four “false positives.” Contemporary technology is little better: at best, three false positives for every two true positives. The best-informed specialists say that accuracy topped out a decade ago; further improvement is unlikely. All prediction instruments use ethically unjustifiable information.*<sup>22</sup>

Given the lack of ability to predict risk, it makes no sense to give heightened deference, much less complete authority, to mental or behavioral health professionals in making predictions about risk. OCR is wrong in assuming that these professionals have special expertise that makes them particularly accurate in predicting health and safety risks.

Moreover, granting extra deference or complete authority to mental health professionals would send the message that the only way to keep mental health information private is to avoid treatment. As OCR has previously stated, “Ensuring strong privacy protections is critical to maintaining individuals’ trust in their health care providers and willingness to obtain needed

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<sup>20</sup> *Id.*

<sup>21</sup> American Psychological Association, *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>.

<sup>22</sup> Michael Tonry, *Predictions of Dangerousness in Sentencing: Déjà Vu All Over Again*, *Crime and Justice—A Review of Research*, Vol. 48, Spring 2019, [https://papers.ssrn.com/sol3/papers.cfm?abstract\\_id=3297789](https://papers.ssrn.com/sol3/papers.cfm?abstract_id=3297789).

health care services, and these protections are especially important where very sensitive information is concerned, such as mental health information.”<sup>23</sup> Granting special deference to mental health professionals could break individuals’ trust and prevent them from getting the help they need.

In its Request for Comments, OCR asks for public input as to whether reducing the standard to a “reasonably foreseeable threat” would discourage individuals from seeking treatment. Lowering this privacy standard is problematic and would deter treatment as individuals would fear unnecessary and inappropriate disclosures. The results of a nationwide Harris Poll indicate that “one in six [adults] (17%) [representing 38 million persons] say that they have withheld information, and this rises to 21 percent among those who are in only fair or poor health.”<sup>24</sup> As stated by Deven McGraw, former Health Privacy Project Director at the Center for Democracy & Technology, “the consequences of this climate of fear are significant – for the individual, for the medical community, and for public health.”<sup>25</sup> Fear gives rise to patients avoiding treatment as well as to the quality of care received in treatment to suffer.<sup>26</sup>

**c. *Removing the Minimum and Necessary Standard In Relation to the Coordination of Care and Permitting Disclosure of Personal Health Information to Third Parties Negatively Impacts Privacy Protections.***

The Privacy Rule currently requires covered entities to use, disclose, and request only the minimum amount of information necessary to meet their legitimate purpose, except when the information is for disclosures or requests for treatment purposes. OCR reports that covered entities are confused by this rule and therefore proposes expanding the exception to the minimum necessary standard for treatment including for care coordination and case management activities with respect to an individual. This is not the right approach.

Instead of expanding the already broadly worded provision to avoid misinterpretation of the law, the provision should be clarified to providers through training to further protect patient privacy.<sup>27</sup> Exempting providers from employing the minimum necessary standard when coordinating care may deter individuals with serious mental illness from seeking treatment due to concern that information that they do not want to be shared, even when it concerns care coordination, would be made available to others.<sup>28</sup>

Additionally, OCR proposes to expressly permit covered entities to disclose protected health information to social services agencies, community-based organizations, HCBS providers, and other similar third parties that provide health-related services to specific individuals for

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<sup>23</sup> U.S. Dep’t of Health and Human Services, Office for Civil Rights, *HIPAA Privacy Rule and Sharing Information Related to Mental Health*, 1 (Dec. 2017), <https://www.OCR.gov/sites/default/files/hipaa-privacy-rule-and-sharing-info-related-to-mental-health.pdf>.

<sup>24</sup> David Krane, *The Harris Poll #27*, THE HARRIS POLL (March 26, 2007), <https://theharrispoll.com/wp-content/uploads/2017/12/Harris-Interactive-Poll-Research-Health-Privacy-2007-03.pdf>.

<sup>25</sup> Statement of Deven McGraw, Director, Health Privacy Project, Center for Democracy & Technology (April 26, 2013), <https://www.cdt.org/files/pdfs/McgrawHIPAAtestimony.pdf>.

<sup>26</sup> *Id.*

<sup>27</sup> *See id.*

<sup>28</sup> *See* Pamela Sankar, *Patient Perspectives of Medical Confidentiality*, 18 J. GEN. INTERNAL MED. 659, 659 (2003).

individual-level care coordination and case management, including activities that constitute treatment or health care operations. Changing this provision would deter individuals from seeking treatment because they may not want their personal health information to be shared with third party agencies regardless of whether the agencies are performing services related to their health.

OCR posed a Request for Comments on whether the changes in privacy from this provision would have unintended negative consequences, in particular, on populations including individuals with disabilities and people with mental health conditions. The proposed changes would have very harmful consequences for people with disabilities, including those with mental health disabilities.

Individuals with disabilities have particular reasons to be concerned about unwanted disclosure of their protected health information to others, including other health providers. Unwanted disclosure of disability-related information lead to many types of harms, including disability-based discrimination if that information is then relayed by social services providers to employers, landlords, or others. While OCR seems to assume that as much disclosure as possible is important for purposes of care coordination and case management, there are important reasons why people with disabilities may not want disclosures to be made to other healthcare providers without consent. Decades of research have chronicled the pervasive discrimination against individuals with disabilities in medical practice. OCR itself has [described](#) how medical practitioners' inaccurate and uninformed views of disabled lives as less valuable or lower quality than others have resulted in people with disabilities receiving poorer quality care, being denied treatment, or otherwise experiencing discrimination. A recent large-scale survey found that 82% of doctors surveyed reported a belief that people with significant disabilities have a worse quality of life than people without disabilities.<sup>29</sup>

These concerns are also true for individuals with mental health disabilities. When mental health information is shared unnecessarily, it increases the danger that individuals with a psychiatric diagnosis in their records will be subject to inaccurate presumptions about the capacity to make medical decisions, follow provider recommendations, benefit from interventions, and live independently. The phenomenon of diagnostic overshadowing (attributing physical health issues to mental health conditions) is also a real and widespread concern experienced by people with psychiatric disabilities; far too often their medical concerns have gone unheeded and written off as the product of a psychiatric issue.<sup>30</sup> Indiscriminate sharing of PHI also endangers access to housing and other social determinants of health.

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<sup>29</sup> Rebecca Sohn, *Large Majority of doctors hold misconceptions about people with disabilities, survey finds*, STAT, Feb. 1, 2021, <https://www.statnews.com/2021/02/01/large-majority-of-doctors-hold-misconceptions-about-people-with-disabilities-survey-finds/>.

<sup>30</sup> See, A. Vistorte, *et al.*, *Stigmatizing attitudes of primary care professionals towards people with mental disorders: A systematic review*, 53 *Int. J. Psychiatry Med.* 317 (stigmatizing attitudes, like pessimism about treatment adherence, are common among primary care professionals and constitute a barrier to health care). Just as primary care clinicians, care managers also are influenced in their decisions by implicit bias.

3. **Congress Already Considered and Rejected Similar Proposals to Weaken HIPAA Privacy Protections and Expand Disclosures to Family Members and Caregivers**

OCR particularly oversteps its authority in the proposed rule by proposing changes that are similar to—but even more dramatic than—changes that Congress specifically considered and rejected in legislation titled the Helping Families in Mental Health Crisis Act (introduced as H.R. 3717 in the 113<sup>th</sup> Congress and H.R. 2646 in the 114<sup>th</sup> Congress). These bills would have similarly modified HIPAA to lower the bar for disclosure of protected health information to family members and caregivers of individuals with serious mental illnesses—particularly with respect to the dangerousness exception. While Congress passed the Helping Families in Mental Health Crisis Act as part of the 21<sup>st</sup> Century Cures Act, it declined to enact those provisions weakening HIPAA protections and instead enacted provisions requiring OCR to issue guidance *clarifying* HIPAA’s application to a variety of areas, which OCR did. What OCR is proposing now would weaken protections under the HIPAA Privacy Rule even more significantly than what was considered and rejected by Congress. OCR must not finalize those changes.

Weakening the standards of disclosure could have harmful and serious consequences for the individuals that OCR asserts it is trying to protect. We strongly oppose weakening these crucial privacy protections.

Sincerely,

Alabama Disabilities Advocacy Program

American Association of People with Disabilities

The Arc of the United States

Autistic Self Advocacy Network

American Therapeutic Recreation Association

Arizona Center for Disability Law

Association of University Centers on Disabilities

Autism Society of America

Autistic Self Advocacy Network

Bazelon Center for Mental Health Law

California Association of Social Rehabilitation Agencies

Center for HIV Law and Policy

Center for Public Representation

Coelho Center for Disability Law, Policy, and Innovation

Hon. Tony Coelho

Coalition of Texans with Disabilities

CommunicationFIRST

Connecticut Cross Disability Lifespan Alliance

Connecticut Legal Rights Project

Disabilities Law Program of Community Legal Aid Society Inc. (DE)

Disability Law Center of Alaska

Disability Law Center of Massachusetts

Disability Law Center of Utah

Disability Rights Arkansas

Disability Rights California

Disability Rights Connecticut

Disability Rights Center of Kansas

Disability Rights Education and Defense Fund

Disability Rights Florida

Disability Rights Maine

Disability Rights Maryland

Disability Rights Michigan

Disability Rights Montana

Disability Rights Nebraska

Disability Rights New Hampshire

Disability Rights New Jersey

Disability Rights New Mexico

Disability Rights New York

Disability Rights North Carolina

Disability Rights Oregon

Disability Rights Pennsylvania

Disability Rights South Carolina

Disability Rights Texas

Disability Rights Vermont

Epilepsy Foundation

Equip for Equality (IL)

Georgia Advocacy Office

Gould Farm

Independence Northwest (CT)

Intentional Peer Support

Keep the Promise Coalition (CT)

Kentucky Protection and Advocacy Division

The Law Project for Psychiatric Rights (PsychRights)

Legal Action Center

Mental Health Association of Greater Dallas

National Association of Councils on Developmental Disabilities

National Association for Rights Protection and Advocacy

National Center on Domestic Violence, Trauma, and Mental Health

National Center for Parent Leadership, Advocacy, and Community Empowerment (National PLACE)

National Coalition for Mental Health Recovery

National Council on Independent Living

National Disability Rights Network (NDRN)

New York Association for Psychiatric Rehabilitation Services

Northern Marianas Protection & Advocacy Systems, Inc. (NMPASI)

The Texas Council for Developmental Disabilities (TCDD)

United Spinal Association