Executive Summary

In recent years many health professionals, consumers of substance use services, advocates and other concerned individuals have thought long and hard about the most effective ways to address substance use disorders, including how best to increase communication between providers of alcohol and drug treatment and recovery services and other health care professionals while maintaining patient privacy. The laudable efforts of the public and private sectors to create electronic health record (EHR) systems elevate the importance of this issue, raising such questions as whether and how alcohol and drug patient records should be included in EHR systems, and whether the federal law and/or regulations governing confidentiality of drug and alcohol records (42 U.S.C. §290dd-2 and 42 C.F.R. Part 2) should be amended.

The Legal Action Center strongly supports the goals of integrating substance use disorder care more effectively with the rest of health care and improving communication between addiction and other health care professionals. We also believe that strong confidentiality protections for alcohol and drug patient records are just as essential to ensuring that individuals will enter treatment and attain and maintain recovery as when the confidentiality law was enacted in the 1970s. From our experience it is clear that communication can be enhanced without compromising confidentiality or changing the basic framework of the federal alcohol and drug confidentiality law and regulations – and that the advent of electronic health record systems can make achieving these twin goals easier, not harder. This paper explains why the current standards should remain in place, and offers our recommendations for improving care while maintaining privacy protections.

We know that some take a different position on these issues, in what we recognize is a continually evolving discussion about how best to protect privacy and security as we

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1 See, for example, the earlier policy paper developed under the auspices of the George Washington University School of Public Health and Services, *A Delicate Balance: Behavioral Health, Patient Privacy, and the Need to Know* (March 2008), co-authored by J. Zoe Beckerman, Joy Pritts, Eric Goplerud, Jacqueline C. Leifer, Phyllis A. Borzi, Sarah Rosenbaum and David R. Anderson (and on which the Legal Action Center and numerous other stakeholders were consulted), available at [http://www.chcf.org/documents/chronicdisease/ADelicateBalanceBehavioralHealthAndPrivacyIB.pdf](http://www.chcf.org/documents/chronicdisease/ADelicateBalanceBehavioralHealthAndPrivacyIB.pdf).

A variation of this paper, by the same authors, was published by BNA in its Health Care Policy Report (Vol. 16, No. 2, Jan. 14, 2008) under the title *Health Information Privacy, Patient Safety, and Health Care Quality: Issues and Challenges in the Context of Treatment for Mental Health and Substance Use*.
develop a national strategy to replace paper with interconnected electronic systems for collecting, storing and transferring individuals’ health information.\(^2\) But we also know everyone has the same goal of identifying the policies and practices that will encourage health care providers to talk to their patients about substance use disorders and protect the confidentiality of those who seek treatment. We welcome dialogue and discussion with everyone to achieve that all-important goal.

In summary, we believe:

-Ensuring enhanced confidentiality protections for people receiving substance use disorder care remains as essential as ever. The federal law and regulations governing Confidentiality of Alcohol and Drug Patient Records strike a sensible and workable balance by requiring alcohol and drug patients’ informed consent for disclosure in most circumstances, with limited exceptions that allow these individuals’ health care providers to share that information when needed to provide safe, effective health care. In contrast, the HIPAA approach, which allows virtually unfettered disclosure of alcohol and drug patient records without individual patient consent to the full range of individuals and organizations involved in law enforcement, health care payment, and health care operations, and allows those entities to redisclose those records without restriction, would keep many people from entering critically needed treatment for substance use disorders. Their justified fear of being arrested and prosecuted, losing custody of their children, and suffering employment, insurance and other discrimination would overwhelm their desire to obtain care. Indeed, many have criticized HIPAA for its insufficient protection of patient privacy in these and other contexts, and people with substance use histories unfortunately are more stigmatized than most recipients of health care.

-Much progress can and should be made in integrating substance use disorder care more effectively with the rest of the health care system. But the federal alcohol and drug patient confidentiality protections are not a major barrier to that goal, since they provide the tools (medical emergency exception, consent forms, qualified service organization agreements, etc.) necessary to facilitate communication. The much more significant problems are that other health care providers often fail to ask about alcohol and drug use history and treatment. When they are asked, many patients are afraid to tell for fear they will not receive the health care they are seeking. Addressing those problems is critical to any successful effort to improve communication and integration of substance use disorder and other health care.

\(^2\) These discussions are gaining even more momentum following the enactment of the American Recovery and Reinvestment Act (ARRA) in early 2009, and the work now being undertaken to implement the health information technology provisions of ARRA, called the Health Information Technology for Economic and Clinical Health Act (HITECH). The HITECH Act is designed to promote the development of the governing policies, standards and technological infrastructure for what is envisioned as a nationwide health information network. See the ARRA legislation, including Subtitle D (Privacy) of its HITECH provisions, at http://frwebgate.access.gpo.gov/cgi-bin/getdoc.cgi?dbname=111_cong_bills&docid=f:h1enr.pdf.
• Electronic health record (EHR) systems can and should be constructed so that alcohol and drug patient records are included and shared with other treating professionals as allowed by the federal confidentiality rules. The technology exists to do this, and, as a result, the adoption and use of EHR systems has the potential to dramatically improve the communication of information about substance use treatment to other health care providers, without compromising patient confidentiality. But we must make sure that EHR systems are constructed correctly, and that substance use disorder and mental health providers receive the resources, technology and technical assistance they need to participate.

• If the current federal alcohol and drug confidentiality rules need to be improved to improve communication, the focus should be on revisiting the federal government’s interpretation of the existing law and regulations to determine if there are ways to achieve that goal without compromising the fundamental principles of the law and regulations. Amending the underlying statute would create great – and we strongly believe unacceptable – risk that bedrock protections could be eviscerated during the legislative process. We recommend that a public/private partnership – involving the Substance Abuse and Mental Health Services Administration, single state authorities, the recovery community, substance use disorder and health care providers and experts and legal experts – engage in a deliberative, consensus-building process to identify how best to improve communication between substance use disorder and other health care professionals while maintaining critical privacy protections.

Discussion

The Importance of Maintaining the Current Federal Law and Regulations Protecting Confidentiality of Alcohol and Drug Patient Records


The federal government recognized that without a strong guarantee of privacy, people in need of alcohol and drug care would be afraid to enter treatment lest they be arrested and prosecuted; lose custody of their children or parental rights; lose their jobs (for example, current illegal drug users are not protected under anti-discrimination laws such as the Americans with Disabilities Act and thus people seeking help for their drug problems can legally be fired); be denied health care; be excluded or evicted from public housing; or be unable for the rest of their lives to obtain health, disability or life insurance. Any and all of these can forever affect an individual’s career path and ability to provide for his/her family or even cost individuals their liberty.
Furthermore, uncontrolled disclosure of information identifying individuals with alcohol or drug problems also has negatively affected many of these patients’ access to health care itself, and the quality of care they receive. Denial of insurance and discriminatory or poor quality treatment by many “mainstream” health care providers of patients identified as having drug or alcohol problems unfortunately continue to occur all too frequently.

Given all these problems, it is not surprising that a recent study in the *Journal of the American Medical Informatics Association* entitled “Openness of patients' reporting with use of electronic records: psychiatric clinicians' views” found that of the outpatient mental health clinicians surveyed:

- 83% disagreed with including their own psychiatric records among routinely accessed EHR systems;
- 80% of respondents said that if they were a patient, they would not want health care providers to have the ability to routinely access their mental health records; and
- 63% said they are less willing to record highly confidential information in EHRs compared with paper records.

The researchers write that the survey findings demonstrate that people involved with mental health care are particularly sensitive to EHR privacy and security issues (Monegain, *Healthcare IT News*, 12/16). While we know of no similar study of substance use disorder professionals, we expect they would be at least as concerned about the unfettered disclosure of their records to the rest of the health care system.

Unfortunately, these risks are as real today as they were three and a half decades ago. Law enforcement still seeks alcohol and drug treatment records on a regular basis to pursue criminal investigations of patients, people with substance use disorders often lose custody of their children, and a poll conducted in 2001 for Faces and Voices of Recovery by Peter D. Hart Research Associates found that 24% of people in recovery report having suffered employment and/or insurance discrimination, with 12% reporting they had personally been denied a job or promotion. This is why the federal law and regulations that protect the confidentiality of alcohol and drug records (hereafter referred to as “42 C.F.R. Part 2”) ordinarily allow disclosures by an alcohol and drug program only by way of an individual's voluntary, prior informed consent, in a medical emergency or when a treatment program has signed Qualified Service Organization/Business Associate Agreements with the recipient.

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This governing principle – which also underlies most state laws protecting the confidentiality of mental health, HIV and other highly sensitive and still stigmatizing health information\(^5\) – is much different from HIPAA in several important respects. Unlike HIPAA,\(^6\) 42 C.F.R. Part 2’s limitations on disclosure apply to communications of alcohol and drug patient information to payors and to a patient’s other health care providers when disclosures are sought or are being made for purposes of the individual’s treatment for other health conditions. Also unlike HIPAA, which bows to state laws that mandate disclosure to law enforcement and for litigation, including judicial and administrative hearings (such as divorce and child custody proceedings) as soon as a health care provider receives a subpoena, judicial or administrative order, or even a discovery request, 42 C.F.R. Part 2 requires a special court order, predicated on the satisfaction of much higher standards before disclosure can be made to law enforcement.\(^7\)

In our view, and based on our extensive experience over 30 years, this is the right and the absolutely essential approach for sharing this highly sensitive and stigmatizing health information, which so often has been used to discriminate against people with substance use disorders. 42 C.F.R. Part 2 has been the bulwark, and indeed an essential precondition, to bringing people in need of substance use disorder care into treatment and keeping them there, to effectively coordinating their care, and to protecting them from discrimination.\(^8\) Allowing virtually unfettered disclosure of alcohol and drug patient records without consent to the full range of individuals and organizations involved in law enforcement, health care payment, or health care operations and allowing those entities to redisclose those records without restriction – as HIPAA does – would result in many people not obtaining the care they need for fear of being arrested and prosecuted, losing custody of their children, and suffering employment, insurance and other discrimination.

Indeed, many have criticized HIPAA for its insufficient protection of patient privacy in these and other contexts, and people with substance use histories unfortunately are more stigmatized than most recipients of health care. Many health privacy experts and consumer advocates are expressing deep concern that HIPAA wrongly deprives health


\(^7\) For example, under 42 C.F.R. Part 2, a court ordinarily may not even order disclosure of treatment records for the purpose of prosecuting a patient. See 42 C.F.R. §§ 2.61 – 2.65.

\(^8\) While – unfortunately in our view – 42 C.F.R. Part 2 does not contain a “private right of action” that would enable patients whose confidentiality rights are violated to bring a lawsuit to enforce their rights, government regulators and treatment programs themselves have worked hard to ensure its enforcement.
consumers of the ability to use consent to control whether, when and how health providers involved in their care may gain access to and use their health information.

The very real risks to and breaches of individuals’ privacy resulting from adoption of the HIPAA standard have been heightened by the advent of electronic health records and development of interoperable networks designed to link multiple EHR systems together.\(^9\) Indeed, rather than driving many in the direction advocated by “Improving Safety and Quality of Care,” recent developments are prompting widespread calls for adoption of broader protections like those afforded by 42 C.F.R. Part 2 and parallel state and federal laws, laws that offer stronger, not HIPAA’s far weaker, safeguards to assure the privacy of sensitive and stigmatizing health information. This is the case with the reports and recommendations issued by the National Committee on Vital Health Statistics in its consensus-driven “Recommendations on Privacy and Confidentiality, 2006-2008” – which the Office of the National Coordinator has recently agreed to pay close attention to – and by numerous other stakeholders advocating such solutions.\(^{10}\)

While allowing all alcohol and drug patient information to flow to all parts of the health care system without restriction may seem benign or even desirable at first blush, we believe it is likely that such a change would backfire, resulting in disclosures that damage the lives of patients and their families more often than improve their care. If the rules were changed to allow disclosure to other health care providers without patient consent and without the accompanying notice prohibiting redisclosure, sensitive information would inevitably be redisclosed to others even further removed from the patient’s care, such as law enforcement and payors, with disastrous results, including unwillingness of many in need of care to obtain it.\(^{11}\) The current requirements that patients consent in writing to disclosures to other health care providers, and that the holder of the records notify the recipients that they must obtain authorization before making redisclosures, has imposed minimal burdens and has succeeded in most circumstances in protecting patients from the consequences of unauthorized disclosure.

Adopting the HIPAA standard to allow health care providers, virtually without restriction, to obtain alcohol and drug records and redisclose them to law enforcement


\(^{11}\) This is the likely result even if 42 C.F.R. Part 2’s prohibition on redisclosure is retained, since most health care providers are more accustomed to the permissive redisclosure standards of HIPAA.
and payors likely would result in great harm to many patients, immediately followed by unwillingness of many in need of care to come forward to obtain it.

**Improving Integration of Substance Use Disorder and Other Health Care Without Weakening Patient Confidentiality**

Many substance use disorder and health care experts advocate that improving integration of substance use disorder treatment with other health care, including facilitating better communication, should be a major national priority. The recently released policy paper, “Improving Safety and Quality of Care,” is one of a number that has taken this position, raising important issues regarding the need to ensure effective, coordinated health care. We wholeheartedly agree that there is an urgent need to achieve these goals.

Unlike the authors of “Improving Safety and Quality of Care,” however, we strongly believe that communication and care coordination can be improved without changing the important underlying principles and requirements of 42 C.F.R. Part 2. In this, we share the views of those who wrote an earlier policy brief on this issue urging that the “Delicate Balance” between existing federal and state health privacy laws can and should be maintained. ¹²

In contrast, “Improving Safety and Quality of Care” proposes what it calls a “modest adjustment” that would permit physicians and health care providers to freely share information – the adoption of the HIPAA standard (45 C.F.R. Parts 160 and 164). The adoption of the HIPAA standard, however, is far from being a modest proposal and would be far-ranging in its effect, opening up disclosures of drug and alcohol patient information for many purposes far beyond the coordination of health care. Since, as discussed above, HIPAA also allows the complete flow of information for payment and health care operations, health care providers and insurance companies and other payors would be able to freely disclose and redisclose a person’s substance use records without patient consent. Going beyond health care delivery activities, 45 C.F.R. § 164.512 allows for a much more open flow of information, without the patient’s written consent, for a whole host of other purposes, including to the police and other law enforcement agencies, and for litigation, including judicial and administrative hearings.

The proposed wholesale restructuring of 42 C.F.R. Part 2 is premised on the view that the federal law and regulations are the reason physicians are unaware of their patients’ alcohol or drug use. This premise is flawed for two reasons. First, there are many reasons, unrelated to 42 C.F.R. Part 2, why doctors are unaware of (and insufficiently involved in the screening, diagnosis, and referral for treatment of) their patients’

substance use. Second, the premise is based on an incomplete interpretation of 42 C.F.R. Part 2 that fails to take into account all the provisions that currently allow the disclosure of information for treatment purposes. It is this faulty premise which leads, in our opinion, to an unnecessary and unacceptable recommendation that the law and regulations should be amended to conform to the HIPAA standards of sharing information. If there are any legitimate concerns that cannot be addressed under the current interpretations of 42 C.F.R. Part 2, a more appropriate response, we suggest, would be a reexamination of those interpretations rather than a wholesale adoption of HIPAA.

We address each of these issues in order.

**Reasons for Physicians’ Lack of Knowledge of Patients’ History of Substance Use**

“Improving Safety and Quality of Care” notes that some physicians are unaware of their patients’ substance use histories and use of medications to treat their addiction. Because of this lack of information, these physicians prescribe medications that interact dangerously with those medications already being taken by patients to treat their addiction. Citing a paper by Constance Weisner and others including colleagues at Kaiser Permanente, “Improving Safety and Quality of Care” attributes the lack of information on the part of physicians about their patients’ history of addiction to 42 C.F.R. Part 2 – a conclusion that the Weisner study does not support. The Weisner study, in fact, makes a compelling case that there are a number of reasons unrelated to 42 C.F.R. Part 2 that contribute to physicians not knowing about their patients’ substance use histories, including:

- some patients may not be forthcoming about their addiction history due to fear of stigma, discrimination or legal sanctions;
- some patients may not be forthcoming due to inappropriate drug seeking; and
- physicians who do not receive adequate training about addiction often do not ask their patients, beyond cursory (if any) questions, about their use of substances.

The Weisner study does not recommend that the federal alcohol and drug patient confidentiality law and/or 42 C.F.R. Part 2 be amended.

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We wholeheartedly endorse Weisner’s recommendations that more effective early detection, screening, assessment, and clinical management processes be developed. Physicians must receive more training in addiction medicine so that they can properly assess the appropriateness of prescribing opioid therapy for patients with substance use problems and provide better patient care overall. Indeed, if physicians engage their patients in conversations about alcohol and drug use, patients will be more likely to share this information.


“Improving Safety and Quality of Care” asserts that 42 C.F.R. Part 2’s requirement that protected information cannot be disclosed “unless authorized by the patient” is not workable in the current health care system.\textsuperscript{14} We disagree.

“Improving Safety and Quality of Care” offers a number of scenarios where a primary care or emergency room physician does not provide important or optimal care to a patient because the doctor does not know the patient’s substance use history. Implicit in these scenarios is the assumption that patients will not consent to disclosures about their alcohol and drug histories and thus these doctors must be able to gain access to this information without consent. In fact, as noted above, physicians frequently do not ask patients about their substance use histories or try to obtain consent. Many, if not all, of the issues raised in these scenarios could be resolved by the physician merely asking the patient about his or her substance use and treatment and requesting that he or she sign consent forms.

Current protections under 42 C.F.R. Part 2 that prohibit physicians from redisclosing the information without patient consent make it more likely that the patient will agree to sign such a consent. If, after consideration of all factors, a patient does not want to authorize disclosure due to fear of discrimination or other harmful consequences, we strongly believe that the patient should retain the right to decline to consent and prevent the disclosure.

Having said that, the federal alcohol and drug confidentiality law identifies a number of circumstances in which records may be disclosed for treatment purposes without patient consent. Some of the most useful options enabling communications without consent for treatment purposes are:

- The medical emergency exception: permits alcohol and drug programs to make disclosures to medical personnel – including mental health and medical care providers – even without a patient’s consent to the extent necessary to meet a bona fide medical emergency affecting a patient or any other person. (42 C.F.R. § 2.51.)

\textsuperscript{14} The one-page paper that accompanies “Improving Safety and Quality of Care”, titled “Modernize Federal Addiction Confidentiality Law and Regulations,” mentions the medical emergency provision as well.
- Qualified Service Organization Agreements (similar to HIPAA’s Business Association Agreements): these agreements allow programs to establish mutual referral or services arrangements with their patients’ other health care providers, including mental health, primary or specialty care providers, and allow both parties to the QSOA/BA to communicate freely with one another as needed to enable them to plan, provide and coordinate their care of the patient. Patient consent is not needed when these agreements are in place. (42 C.F.R. § 2.12(c)(4).)

- Internal Program Communications – in situations like the one described by Weisner where a health care entity has different departments, including one that provides substance use disorder treatment, information can be shared with other providers within the entity if their work would facilitate the provision of the chemical dependence service. (42 C.F.R. § 2.12(c)(3).)

- No patient identifying information: information that does not “identify a patient as an alcohol or drug abuser” can be disclosed. Thus, for example, disclosure of information about medication for depression would not be barred by 42 C.F.R. Part 2 if, as in one scenario, that did not reveal alcohol or drug patient identifying information. (42 C.F.R. §2.12(a)(1).)

As stated above, we believe that 42 C.F.R. Part 2 strikes the right balance in ordinarily requiring consent for disclosure but allowing disclosures without consent if any of the exceptions above pertain. We further believe that training of health care providers and elimination of discrimination against people in treatment are the keys to integrating care, not eliminating the very confidentiality provisions that often protect patients from discrimination and other harm.

**Electronic Health Record Systems Have the Potential to Facilitate Needed Communication While Maintaining Existing Confidentiality Protections**

To the extent that some suggest that the federal alcohol and drug confidentiality rules create a significant burden to the inclusion of alcohol and drug records in electronic health record systems, the Legal Action Center respectfully disagrees. We have consistently endorsed the goals underlying "e-health" initiatives and believe that giving both patients and their health care providers effective, real-time access to health information that is relevant to their care through an integrated electronic health record system or network can improve the quality and coordination of the care that individuals receive, for behavioral (substance use/mental health) as well as physical health conditions.

Indeed, we believe that if implemented correctly, computer technology makes it easier, not harder, simultaneously to protect the privacy of records and facilitate communication in appropriate circumstances. Software that is correctly designed can provide for electronic communications but also can contain blocks that limit disclosures to those who
are specifically authorized. Many hospitals and other health care providers have long used computer technology in this way, and we do not see any reason why electronic-health record systems cannot do so with equal success. In fact, we have been told repeatedly by software experts that EHR systems can be constructed so as to allow the flow of patient information when appropriate while complying with all the requirements of 42 C.F.R. Part 2.

For these reasons, far from 42 C.F.R. Part 2 creating obstacles to including alcohol and drug patient records in electronic health record systems, we see the proper construction of electronic health record systems as the solution to the problem of how to simultaneously facilitate communication and ensure compliance with 42 C.F.R. Part 2.

However, it is critically important that federal and state authorities take two essential public policy steps:

- EHR systems must be designed so that substance use disorder records are included and the requirements of 42 C.F.R. Part 2 are met, and
- Substance use disorder and mental health providers must receive the resources, technology and technical assistance they need to participate in EHR systems.

**Begin a Consensus Process to Identify the Best Ways to Improve Integrated Care While Maintaining Essential Confidentiality Protections**

As explained above, we believe that the major barriers to improving communication between the substance use disorder system and the rest of the health care system are not in the federal alcohol and drug patient confidentiality rules but instead are:

- Need for electronic health record systems that incorporate substance use disorder records and are designed to follow the federal confidentiality rules;
- Lack of resources that inhibit many providers of substance use disorder care from participating in electronic health record systems;
- Lack of understanding of many health care professionals about substance use disorders, the requirements of the federal confidentiality rules, and how to obtain alcohol and drug patient records; and
- Fear on the part of many substance use disorder patients that they will be discriminated against if they reveal their treatment status.

We strongly urge that the public and private sectors take the necessary steps to address all these problems.

At the same time, we are open to discussion and dialogue about whether there are ways that the federal alcohol and drug patient confidentiality rules could be improved to facilitate better communication and integration between the substance use disorder field
and the rest of the health care system. If there are, then the focus should be on revisiting
the federal government’s interpretation of the existing law and regulations to determine if
there are ways to achieve that goal without compromising the fundamental principles of
the law and regulations. For example, the Substance Abuse and Mental Health
Administration could revisit the ruling that Qualified Service Organization Agreements
(QSOAs) cannot be signed between two treatment providers covered by 42 C.F.R. Part 2,
which prevents the use of QSOAs between an alcohol and drug program and a
community mental health center, hospital or clinic that also provides covered alcohol and
drug services. There may also be circumstances which could be considered a medical
emergency that have to date not been clearly delineated as such.

However, we believe that amending the underlying statute is not only unnecessary, it
would create great – and we strongly believe unacceptable – risk that bedrock protections
could be eviscerated during the legislative process.

To address all these issues and determine the best ways to move forward, we recommend
that a public/private partnership led by SAMHSA/CSAT engage in a deliberative,
consensus-building process to identify how best to improve communication between
substance use disorder and other health care professionals while maintaining critical
privacy protections. Key stakeholders should include the federal government and single
state authorities, the recovery community including persons both in long-term and newly
in recovery and their family members, substance use disorder and health care providers,
experts, researchers, legal experts and advocates. Together, we can determine what is
best for people in need of substance use disorder care, while protecting their rights, and
craft our nation’s public policies accordingly.