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Adolescent Confidentiality and Privacy Under the Health Insurance Portability and Accountability Act

by Rebecca Gudeman

Introduction

Adolescents are more likely than adults to have their state-protected right to medical confidentiality violated by providers or insurers. New federal privacy rules obligate providers and insurers to better safeguard the confidentiality of information protected under state law. This article analyzes whether the new federal rules will help reduce violations of adolescent confidentiality.

While parents generally have a right to medical information about their children, many states have granted teens the right to medical confidentiality in specific situations. This right requires a provider to obtain the adolescents' consent before releasing information to parents. Such confidentiality statutes help to ensure that adolescents are willing to seek the care they need.

However, despite statutory protection, parents sometimes get access to confidential health

information, without the adolescents' consent, through billing, phone calls to the home, records and other administrative channels. Adolescents are uniquely vulnerable to such breaches because of their status as dependent minors. Unfortunately, these confidentiality breaches undermine the effectiveness of the privacy protections.

In late 2002, the U.S. Department of Health and Human Services (HHS) published new personal health privacy regulations under the Health Insurance Portability and Accountability Act of 1996 (HIPAA¹). The regulations were designed in part to make providers, insurers, and others more accountable for their handling of confidential infor-

mation. However, do the HIPAA regulations address the specific confidentiality violations to which teens are most vulnerable?

This article begins with a brief overview of state adolescent confidentiality rights. It then introduces the HIPAA regulations. The next section presents examples of the most typical violations of adolescent confidentiality and assesses how well the HIPAA regulations address such breaches. The article continues with a brief review of other relevant

HIPAA regulations, including enforcement provisions. It concludes with some recommendations on how advocates can use HIPAA to foster a better understanding among providers and insurers of adolescent confidentiality issues.

Confidentiality Rules in Adolescent Health Care

Because adolescents are not yet adults, parents have the right to make most decisions on their behalf. This includes the right to receive information about most adolescent health care. However, states have carved out exceptions to this general rule. First, states established consent exceptions. Today, the great majority of states allow minors to give their own consent for

(continued on p.2)

¹Pub. L. No. 104-191, 110 Stat. 1936 (1996). For an overview of HIPAA's health privacy regulations, see *Summary of HIPAA Privacy Rule*, Health Privacy Project, Georgetown University (2002), http://www.healthprivacy.org/usr_doc/RegSummary2002.pdf; Joy Pritts, *Implementing the Federal Health Privacy Rule in California: A Guide for Health Care Providers*, California HealthCare Foundation (2002), <http://www.chcf.org/topics/view.cfm?itemID=19670>; see also Catherine Weiss, *Protecting Minors' Health Information Under The Federal Medical Privacy Regulations*, ACLU Reproductive Freedom Project (2003), <http://www.aclu.org/ReproductiveRights/ReproductiveRights.cfm?ID=12118&c=222>.



Marilyn Nolt

by Rebecca Gudeman

(continued from p. 1)

Adolescent Confidentiality

the treatment of sexually transmitted diseases (STD), as well as alcohol and drug abuse services. The majority of states also permit adolescents to provide their own consent for prenatal care and contraception. In many states, minors can give their own consent to five or more distinct services. In addition, in many states, minors who have reached certain stages in life, such as marriage or parenthood, can give consent for

states grant providers the discretion to decide when to notify parents about a minor's services, but parents have no absolute right to the information. When minors have a right to confidentiality under state law, providers generally cannot release protected information without the minor's consent. The adolescent may choose to involve parents in his or her care, but providers may not make that choice for them.

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their own care.²

States also have carved out confidentiality exceptions that limit parents' rights to access medical information. Confidentiality exceptions vary across states. A handful of states grant minors a right to confidentiality in almost every service to which the minor can give consent. Others states grant minors a right to confidentiality in certain minor consent-granted services but not others. Alternatively, some

do so. Studies show that for certain conditions, such as drug abuse, mental health problems, and pregnancy, many minors will not seek care if their parents may find out.

Unfortunately, a state-protected right to confidentiality has not always translated to real-world confidentiality. Experience demonstrates that information protected in the provider's examining room nevertheless may be disclosed to parents through administrative channels. Many factors, including the fact that many state confidentiality laws do not specifically

address administrative responsibilities, lead to these disclosures. Unfortunately, for some teens, the increased risk of exposure created by this loophole eviscerates the value of adolescent confidentiality laws.

HIPAA's Privacy Rules

HIPAA's privacy rules were designed to address consumer concerns about how well-guarded "protected medical information" really is. Three kinds of organizations must comply with HIPAA's privacy regulations: health care clearinghouses, most health care providers³, and health insurance plans (including Medicaid and SCHIP⁴ programs).⁵

The rules establish minimum privacy standards.⁶ In general, the regulations do four things:

1. They limit how and when an entity may use health information without individual consent;
2. They give individuals more control over how their personal information is used;
3. They establish certain administrative procedures that organizations must implement to assure information is protected;
4. They establish an avenue of recourse when privacy is compromised.

³Standards for Privacy of Individually Identifiable Health Information, 45 C.F.R. §§ 160.102(a), 164.104 (2002) (regulations apply to any "health care provider who transmits any health information in electronic form in connection with a transaction covered by" HIPAA).

⁴The State Children's Health Insurance Program, 42 U.S.C. § 1397aa et seq.

⁵*Id.*

⁶See 45 C.F.R. §160.203.

In so doing, the regulations address issues of unauthorized administrative disclosures by providers and insurers. But do the HIPAA regulations protect against the specific breaches teens most often face?

Applying HIPAA to Adolescent Confidentiality Breaches

Legally protected information gets revealed in many ways. However, the leaks that most often plague teens generally fall into one of a few categories. This section will review five of these. After describing the particular type of disclosure, each subsection then will review the applicable HIPAA regulations to assess whether HIPAA provides any protection.

1. Provider and Insurer Confusion over What Information is Protected

In California, minors age 12 or older who have been raped have a right to give their consent to care and keep their treatment confidential from parents. Minors who have been sexually assaulted also have a right to give their consent to care, but providers must attempt to notify their parents of any treatment provided.⁷ Providers dealing with both rape and sexual assault victims often become confused as to whose information must be protected and whose parents must be notified.

⁷Cal. Fam. Code §§ 6927, 6928 (consent and confidentiality laws); Cal. Civ. Code §§ 56.10-.11 (additional confidentiality provisions).



Marilyn Noit

While a few states give minors the right to confidentiality in almost every medical service to which they can give consent, most states do not. With up to ten different minor consent rules in each state, and potentially different confidentiality laws for each, providers must understand a complicated web of rules. In addition, in every state, there are circumstances in which providers must breach confidentiality – for example, to report suspected child abuse. This complexity means providers and insurers sometimes mistakenly allow access to what should be confidential information.

Does HIPAA address this problem? It does not. The HIPAA regulations establish that when an individual provides consent for personal care, that individual generally has a right to control access to the medical information.⁸ However, the

regulations specifically exempt minors from this national standard when it comes to controlling parental access.⁹ The regulations make clear that state law, not federal law, determines parental access to confidential adolescent medical information. Thus, HIPAA does not simplify or create new confidentiality standards.

2. Failure to Segregate and Safeguard Records

Marcela's mother asks the receptionist at Marcela's doctor's office for a copy of her daughter's medical records to send to her summer camp. The receptionist copies the whole file without looking at its contents. Later, while glancing over the paperwork, Marcela's mom notices that at Marcela's last physical, Marcela asked the doctor about contraception. The doctor had written "minor consent – confidential" next to this part of the record, but the receptionist had not blacked it out in the mother's copy.

⁹§ 164.502(g)(3)(ii).

Often, parents and minors each have rights to control access to different parts of the minors' medical records. When parents have a right to obtain some, but not all information, the information must be carefully recorded and separated in provider files. Some teen health providers have systems to separate information. For example, they record confidential adolescent information on different colored paper, or they flag protected information with a sticker, and office staff is trained to look for these markers. However, most providers do not have administrative systems to ensure such separation. Without these, inadvertent disclosures are much more likely.

Does HIPAA provide any protection? Yes, it does. In general, the regulations prohibit providers and insurers¹⁰ from using health information without an individual's permission.¹¹ Inadvertent breaches due to administrative carelessness, as in this case, violate this rule. In order to protect against inadvertent breaches, the HIPAA regulations require that providers and insurers establish specific administrative protections. They must:

- Seek written consent for most disclosures;¹²
- Seek permission before sharing any information, even a

¹⁰The HIPAA regulations apply to health care clearinghouses, insurers and most providers. Because most accidental disclosures are linked to insurers and providers, this paper will refer only to providers and insurers. This does not mean that health care clearinghouses are exempt from these regulations.

¹¹ §§ 164.508(a)(1), 164.502(a).

¹² § 164.508(a), (b).

patient's name, with family or friends;¹³

- Implement general policies and protocols to assure compliance with the HIPAA privacy rules;¹⁴

- Implement "appropriate administrative, technical and physical safeguards to protect the privacy of protected information" from any intentional or unintentional use in violation of the privacy rules;¹⁵

- Within the office, make reasonable efforts to limit access only to those employees who need it and to the information they need given their duties;¹⁶

- For routine and recurring disclosures, establish policies that limit disclosures to that reasonably necessary to achieve the purpose of the disclosure. For all other requests for disclosure, review them on an individual basis for potential unauthorized disclosures and establish criteria to review non-recurring requests;¹⁷

- Provide training to employees, as necessary and appropriate given each employee's function, on the entity's HIPAA related policies and procedures;¹⁸ Appoint a privacy official "responsible for the development and implementation" of the entity's HIPAA policies and procedures.¹⁹

(continued on p. 4)

¹³ § 164.510. If the minor is not available to agree to or prohibit use, the organization only may disclose if, in the exercise of professional judgment, the organization determines that such disclosure is in the best interests of the minor but only may disclose information directly relevant to the person's involvement with the minor's care. § 164.510(b)(3).

¹⁴ § 164.530(i)(1).

¹⁵ §§ 164.530(c)(1), (c)(2)(i).

¹⁶ § 164.514(d)(2).

¹⁷ § 164.514(d)(3).

¹⁸ § 164.530(b).

¹⁹ § 164.530(a)(1)(i).

⁸See 45 C.F.R. § 160.203 (federal preemption), § 164.501 (defining protected health information), § 164.508(a) (requiring authorization for release), § 164.502 (establishing general disclosure rules).

by Rebecca Gudema

(continued from p. 3)

Adolescent Confidentiality

These regulations specifically require providers and insurers to implement office policies and administrative safeguards to protect records. Further, they mandate training for all staff who deal with records and releases, and require one employee to be responsible for administering these policies. If minors may have a right to confidentiality under state law, providers and insurers must establish technical and physical safeguards that are capable of shielding confidential information from parents.

3. Demands to Waive Confidentiality Rights

Kira goes to her doctor's office for a check-up. The receptionist tells her to fill out some forms while she waits. One form requires Kira to promise to let her parents have access to all of her health records. When Kira asks the receptionist about this document, the receptionist tells Kira that she cannot see the doctor until she signs.

While less common, sometimes adolescents are told that they cannot receive needed services until they waive their rights to confidentiality.

Does HIPAA provide any protection? Yes, it does. The regulations specifically state that organizations cannot obligate

individuals to give up their rights to privacy as a condition for treatment, payment, health plan enrollment, or eligibility for benefits.²⁰

4. Provider Communications to the Home

Darrin asks his provider for an STD test. Two days later, the provider leaves a message on Darrin's family answering machine letting him know that "his test results are in." Darrin's parents begin to ask questions.

This type of situation is not uncommon because minors so often live with their parents.

²⁰ § 164.508(b)(4). However, there are few exceptions: "A health plan may condition enrollment in the health plan or eligibility for benefits on provision of an authorization requested by the health plan prior to an individual's enrollment in the health plan" ... if it's for health plan eligibility, underwriting, or enrollment decisions. See § 164.508(b)(4)(ii).

Does HIPAA provide any protection? Yes, some. Such communications do not automatically violate HIPAA. While HIPAA usually requires written consent before disclosure of any information, even in a phone call, there are exceptions. HIPAA specifically allows the use of medical information without the patient's consent for treatment, payment, and health care operations.²¹ If additional incidental breaches occur in using information for these purposes, HIPAA specifically protects that disclosure.²² These exceptions mean that many communications-related disclosures do not automatically violate HIPAA rules.²³

²¹ § 164.502(a)(1)(ii).

²² § 164.502(a)(1)(iii).

²³ See § 164.502(a)(1)(ii).

However, even if HIPAA does not absolutely bar every phone call home without prior consent, the regulations do give individuals a right to control how providers communicate with them. Individuals have the right to ask a provider or insurer to communicate with them through alternative methods (for example, mail or cell phone) or at alternative locations (for example, a friend's house).²⁴ The regulations require providers to accept all reasonable requests of this nature.²⁵ Further, providers may not require an explanation as to the basis for the request.²⁶ While this right appears to resolve dilemmas like Darrin's, adolescents should be cautious. Ultimately, they must rely on their providers to honor and enforce such requests. While there may be sanctions available against a provider who does not (see *infra*), adolescents whose highest priority is hiding their need for medical service from family and friends may be justified in relying on this contract only with caution.

5. Insurance communications

Sixteen-year-old Maya believes she may be pregnant, but she is afraid to tell her parents. They always told her that if she got pregnant, she would be out on the street. In Maya's home state, a minor can seek pregnancy testing

²⁴ § 164.522(b)(1).

²⁵ §§ 164.522(b)(1)(i), 164.502(h), 164.522(b)(2)(ii) (While such requests do not have to be in writing, entities may require individuals to write their requests. They also may condition accommodation on information as to how payment will be handled; and specification of an alternative address or other method of contact.).

²⁶ § 164.522(b)(2)(iii).



Marilyn Nolt

without her parents' knowledge or consent. So Maya goes to her family doctor for a test, using her parents' insurance policy to cover the service. Two weeks later, her parents receive an Explanation of Benefits (EOB) form from their insurance provider notifying them that Maya received services. That night, Maya finds her angry, anxious parents waiting for her when she gets home from school.



Marilyn Nolt

In addition to at-home contacts as in Darrin's case, some of the most common incidental disclosures of adolescent information are linked to insurance policies in which a parent is the named insured. Even with a right to confidentiality, most minors are still dependents. Therefore, parents often are involved in payment issues.²⁷

Does HIPAA provide any protection? Not really. Because most insurance communications are for the purpose of payment or health care operations, insurers do not need the minor's written consent prior to making disclosures. While some may argue that an EOB form is a disclosure not directly tied to payment, breaches incidental to payment-related disclosures are allowed as well. HIPAA does establish certain boundaries on allowable incidental disclosures. When disclosing information for payment or health care operations, organizations must make

“reasonable efforts” to limit disclosures to the “minimum necessary to accomplish the intended purpose of the disclosure.”²⁸ They also must reasonably safeguard information to limit incidental disclosures pursuant to otherwise permitted uses.²⁹

However, the regulations do not define “minimum necessary” or “reasonably.” Thus, disclosures will depend on how insurers interpret the standards. Whether an EOB like the one in Maya's case goes too far is unclear. What is clear is that the regulations do not bar most payment-related disclosures.

Maya, like Darrin, does have a right to request alternate communications, but this right may be less effective to prevent insurer disclosures. HIPAA states that insurers only need to accept a request to provide information via an alternate path if the minor “clearly states” that disclosing the information involved might “endanger” him or her.³⁰ This additional requirement likely will dissuade

some minors from attempting to exercise the right in the first place. Some teens may find it difficult to express their fears – particularly to an unknown insurer. Many also know that

HIPAA also grants individuals the right to request that a provider or insurer restrict otherwise allowable disclosures.³¹ For example, an individual may ask that an insurer not send benefit letters home. Should an entity accept such a request, the restriction must be honored.³² However, while organizations must consider such requests, they do not need to grant them.³³ If providers and insurers are willing to accept requests, this right could limit insurance disclosures. Whether insurance companies will accept such requests, however, remains to be seen.

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explicitly describing danger may lead to a child abuse report. While teens may be willing to share such information with a provider, they will be less likely to share such personal information with an insurer. In addition, the regulations do not define “endanger.” Is fear of abuse required? What if the minor states she would avoid services if there were a risk her parents might find out? Is lack of service enough to endanger the minor? Further, the regulations do not define “clearly states.” Is a statement that disclosure may endanger the minor enough, or does the minor have to give specific detail? Interpretation of these terms is left to the insurer's discretion, making the efficacy of this option hard to predict.

Other Relevant HIPAA Regulations

The regulations include several additional rules that give individuals better control over their privacy, ensure that organizations comply with the privacy obligations, and use information within allowable parameters. These regulations include the following:

- First, providers and insurers must designate a contact person at their agency who will be responsible for receiving complaints and providing information about the organization's HIPAA policies;³⁴

(continued on p. 6)

²⁷In some states, state law specifically exempts parents from liability for certain services if the minor consented for her own care and the parents knew nothing about it. See, e.g. Cal Fam. Code § 6926(b); see also Haw. Rev. Stat. § 577A-1

²⁸ § 164.502(b)(1).
²⁹ § 164.530(c)(2)(ii).
³⁰ §§ 164.522(b)(1)(ii), 164.502(h).

³¹ § 164.522(a)(1)(i).
³² §§ 164.522(a)(1)(iii), 164.502(c).
³³ § 164.522(a)(1)(ii).
³⁴ § 154.530(a)(1)(ii).

by Rebecca Gudeman

(continued from p. 5)

Adolescent Confidentiality

■ Second, minors who are clients have the right to receive written notice of the organization's privacy practices.³⁵ This notice must meet several specific requirements. For example, it must include adequate notice of disclosures the organization is permitted to make without seeking the client's written consent, the organization's legal duties with respect to the individual, and the individual's rights. The notice also must contain information on how to file complaints, includ-

HHS any time they feel their privacy has not been protected.³⁹

Unfortunately, the right to complain and seek legal remedy is not a powerful enforcement tool. Insurers and providers are left to process their own complaints, and HHS is not required to act on any of the complaints it receives.⁴⁰ In any case, a complaint-driven enforcement mechanism is effective only if consumers know they have a right to complain and are willing to make complaints. Most adolescents will be unaware of their confidentiality rights under HIPAA and state law, and unaware of their right to file complaints. Thus, while the right to file a HIPAA complaint is impor-

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ing the name or title, and telephone number, of a person to contact for further information about the plan's privacy policies, and how to make a complaint.³⁶ If the plan has a Web site, the plan "must prominently post its notice" on the site;³⁷

■ Finally, teens will have a right to file a complaint with both the organization³⁸ and

tant, it may be most helpful as a tool to educate organizations about adolescent confidentiality concerns rather than a tool of true enforcement. This is also true because HIPAA does not establish a private right of action. This means minors cannot use HIPAA to sue an organization that fails to protect confidentiality.

Recommendations

In the end, HIPAA rules and regulations may help to protect confidential adolescent health information. But ultimately, whether HIPAA will reduce the risk of disclosure to a level at which adolescents will feel comfortable seeking confidential care will depend on how organizations interpret and implement many of the regulations.

For this reason, perhaps the biggest contribution HIPAA makes is its reminder to organizations that adolescents are a group with distinct rights which must be respected. HIPAA makes clear that when adolescents have a right to give consent for their own care, organizations must honor their right to be treated as individuals. Once providers and insurers begin to think about teens and their privacy rights and needs as HIPAA requires them to do, they may be more willing to adapt their policies to better suit the particular needs of adolescents.

Meanwhile, adolescent health advocates can foster this awareness by educating organizations about adolescent confidentiality and adolescent HIPAA rights. They can:

- Provide organizations with information on their state's minor consent and confidentiality laws, to ensure the organizations understand when a minor does have a right to confidentiality;
- Educate the privacy officials at each organization about teen

confidentiality concerns and barriers to care;

- Encourage teens to ask for their provider's and insurer's notices of privacy practices;
- Encourage teens to request alternate communications;
- Encourage teens to request a restricted use of information. While organizations do not have to accept these requests, once organizations understand how something like the threat of a phone call may prevent a teen from seeking care, they may be willing to accept more of them;
- Inform teens about their right to file complaints with organizations and encourage them to do so when necessary. While complaints may not result in sanctions or recompense, the complaints will be a valuable education tool for the organizations.

HIPAA should be considered an opportunity for advocates, minors and organizations to work together to improve teen health care.

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³⁵ § 164.520(a).

³⁶ § 164.520(b).

³⁷ § 164.520(c)(3)(i).

³⁸ § 164.530(d)(1).

³⁹ § 160.306(a).

⁴⁰ See § 160.306(c).40 See § 160.306(c).