

# New Medical Records Privacy Rule: The Interface with Teen Access to Confidential Care

By Cynthia Dailard

The notion that confidentiality is key to many teenagers' willingness to seek sensitive health services such as family planning is well established in law. At the federal level, both Medicaid and Title X of the Public Health Service Act guarantee confidentiality to teenagers seeking family planning services. Under numerous state laws, moreover, minors are entitled to consent on their own to a range of sensitive health services. Except in the area of abortion, lawmakers generally have resisted efforts to eliminate these protections by requiring parental consent before a teen can access reproductive health services or by notifying parents afterwards.

Regulations promulgated by the Bush administration regarding the privacy of medical records, however, call these state-level protections into question. The Bush rule, which becomes effective in April, vitiates the long-standing presumption that when teens are authorized to consent to services under state law, they can also expect their medical records to remain confidential. Fortunately, the rule's potential for harm is likely to be mitigated by its deference to both provider judgment and long-standing principles of medical ethics that guide the delivery of confidential care to minors.

## Confidentiality and Consent

Generally, parents have the legal authority to make medical decisions on behalf of their children, based on the principle that young people generally lack the maturity and judgment to make fully informed decisions before they reach the age of

majority (18 in most states). Exceptions to this rule exist, however, such as when medical emergencies leave no time to obtain parental consent and in cases where a minor is "emancipated" by marriage or other circumstances and thus can legally make decisions on his or her own behalf. Some states also have adopted the so-called mature minor rule, under which a minor who is sufficiently intelligent and mature to understand the nature and consequence of a pro-

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posed treatment may consent to medical treatment without consulting his or her parents or obtaining their permission.

Research from as far back as the late 1970s has highlighted the importance of confidentiality to teens' willingness to seek care. Recent research confirms these original findings. For example, a study appearing in 1999 in the *Journal of the American Medical Association (JAMA)* found that a significant percentage of teenagers had decided not to seek health care that they thought they needed due to confidentiality concerns. With respect to reproductive health care, specifically, a 2002 *JAMA* study found that almost half of sexually active teens (47%) visiting a family planning clinic would stop using clinic services if their parents were notified that they were seeking birth control, and another 11% reported that they

would delay testing or treatment for sexually transmitted diseases (STDs) or HIV; virtually all (99%), however, reported that they would continue having sex.

As a result, public policy for over three decades has reflected the understanding that many minors will not seek certain important health services if they need to inform their parents. Today, a significant body of federal and state law explicitly guarantees confidential access to services or does so by implication. Title X, the only federal program dedicated to providing family planning services to low-income women and teenagers, has since its inception in 1970 provided confidential services to people regardless of age (although minors are encouraged to include their parents in their decision to seek services). Additionally, courts have interpreted the federal Medicaid statute to require family planning services to be provided to sexually active minors who desire them on a confidential basis.

Finally, a host of state laws explicitly authorize minors to consent to a range of reproductive health care services (including prenatal care and delivery), as well as substance abuse treatment and mental health care. Currently, all states allow minors to consent to STD testing and treatment services, and 27 states explicitly allow minors to consent to contraceptive services. In some of these states, the decision of whether to inform parents is left to the discretion of the physician as to the best interests of the minor ("Minors and the Right to Consent to Health Care," *TGR*, August 2000, page 4). No state, however, requires parental consent or notification for any of these services. (The only exception is abortion: 31 states have laws in effect requiring the involvement of at least one parent in their daughter's abortion decision; virtually all of these state laws allow minors to apply for a judicial bypass, as required under U.S. Supreme Court

precedent, when they do not want to inform their parents.)

### **From Clinton to Bush**

Implied in all of this is the understanding that disclosure of teens' medical information after they seek treatment would undermine their willingness to consent to services in the first place. Only a few states, therefore, have laws that address explicitly the privacy of teens' medical records. New York law, for example, specifies that parents may not access the medical records of their minor child who has obtained an abortion or treatment for an STD. Similarly, health care providers in Colorado cannot be compelled to release to a parent a minor's medical records related to testing or treatment for STDs or drug addiction. But the vast majority of state laws granting minors the right to consent to services are silent on this front.

The issue of state law and minors' right to control their medical records was thrust center-stage, however, with the enactment of the Health Insurance Portability and Accountability Act of 1996, which required the Secretary of Health and Human Services to develop regulations designed to regulate access to and disclosures of confidential medical information. After a notice and comment period, a final rule was issued during the final days of the Clinton administration in December 2000. The rule spelled out protections for medical records generally and contained specific provisions aimed at minors.

Under the Clinton rule, parents generally were given control of and had access to their minor children's medical records. However, the rule recognized that allowing parents to access their children's medical records in all circumstances would jeopardize teens' willingness to obtain sensitive health services. As a result, the rule allowed minors to

maintain the confidentiality of medical records related to care that they lawfully consented to under state or federal law. (Minors would also control their medical records when their parent agreed to allow a health care provider to examine a teenager privately and maintain that teenager's confidence.) By linking minors' right to medical privacy to their ability to consent to services, the Clinton rule recognized that the state laws allowing minors to consent to services would be meaningless if they did not contain an implied guarantee that those services would remain confidential as well.

Only a few months later, the Bush administration announced in April 2001 that it would propose key changes to the Clinton privacy rule, including changes to address "par-

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ents' concern that the rule limits their right to have access to their children's medical records." The final regulation, published in August 2002, severs the existing link between minors' right to consent to health care and their ability to keep their medical records private. Instead, minors will only control their medical records when states explicitly authorize them to do so. When state law either requires or permits disclosure to parents, the regulation allows the health care provider to comply with that law. But when a state is silent on the subject (as most of them now are), it is up to the health care provider to decide whether to maintain the confidentiality of those medical records or disclose them to a parent requesting access to those records. (In con-

trast, state silence under the Clinton rule meant that the teen's privacy rights would hinge on the state's consent policy.)

### **Unfinished Business?**

While the rule says that the administration "takes no position on the ability of a minor to consent to treatment and no position on how State or other law affects privacy between the minor and a parent," it suggests that states may want to consider laws that spell out parents' rights in this area: "These changes adopted in this Rule provide States with the option of clarifying the interaction between their laws regarding consent to health care and the ability of parents to have access to the health information about the care received by their minor children in accordance with such laws." Thus, a state law granting minors the right to consent to reproductive health care no longer means that the issue of confidentiality is settled in that state.

At the same time, however, the rule does say that the administration "does not want to interfere with the professional requirements...or other ethical codes of health care providers with respect to the confidentiality of health information or with the health care practices of such providers with respect to adolescent health care." In this regard, the Bush rule maintains the status quo that existed prior to the Clinton rule, to the extent that principles of medical ethics and standards of professional medical organizations such as the American Academy of Pediatrics have long dictated that the confidentiality of teens' medical records be maintained when teens privately seek sensitive services. Nonetheless, advocates concerned about teens' reproductive health will need to be vigilant at the state level and may need to consider whether still more needs to be done to fully protect minors' right to obtain confidential care. ⊕