

“Sensitive Information in Medical Records:  
Protecting the Interests of Adolescents”

Testimony of  
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My name is Abigail English, I am the Director of the Center for Adolescent Health & the Law in Chapel Hill, North Carolina. The Center is a nonprofit legal and policy organization that works nationally to support laws and policies that promote the health of adolescents and young adults and their access to comprehensive health care. Two of the primary areas that we address are consent and confidentiality protections and financial access to health care. Our work emphasizes the needs of vulnerable populations of young people. We research laws and policies, provide consultation, disseminate information, and engage in advocacy. I have worked on legal and policy issues in adolescent health since the late 1970s.

I appreciate the opportunity to present testimony today on the important issues related to protecting sensitive information in the medical records of adolescents. First, I will briefly summarize the significance of research findings over the past several decades on the importance of privacy concerns to adolescents. Next I will describe the current legal framework for consent and confidentiality in the health care of adolescents, including the relationship between the HIPAA Privacy Rule, state consent and confidentiality laws, and other federal laws. Finally, I will highlight several important unanswered questions that need to be addressed as health reform is implemented and electronic medical records become more prevalent. A list of relevant background references is included at the end of this testimony. This testimony includes material drawn from an extensive monograph produced by the Center for Adolescent Health & the Law, *State Minor Consent Laws: A Summary*. 3<sup>rd</sup> Edition (2010).

### The Importance of Confidentiality

Findings from more than two decades of research has consistently documented that protecting confidentiality can enhance the likelihood that adolescents will receive needed health care and that limiting confidentiality can impede their access to essential care. Adolescents report that concerns about privacy—specifically concerns about whether or not their parents will be informed—limit their use of health care. This has been indicated both when adolescents report retrospectively on why they did not receive health care and when they respond prospectively about what they would do if parental notification were required for health care they were seeking. Privacy concerns can lead adolescents to delay seeking care or forgo care entirely, and can affect their choice of provider, the candor of their responses to questions about sensitive topics, and their acceptance of specific types of care such as pelvic examinations and testing for STIs and HIV.

### The Legal Framework

The legal framework for consent and confidentiality in adolescent health care includes both state and federal laws. These laws are embodied in constitutional doctrine, statutes enacted by Congress and state legislatures, regulations promulgated by administrative agencies at all levels of government, and cases decided by courts. Notable for determining the consent requirements for adolescents to receive health care are the statutes known as “state minor

consent laws.” Of similar importance for the confidentiality of adolescents’ health information are the federal medical privacy regulations known as the “HIPAA Privacy Rule.” Many other laws have significance in specific circumstances as well, such as statutes providing for the emancipation of minors, court decisions delineating the mature minor doctrine, regulations protecting adolescents’ confidentiality in family planning and substance abuse programs, and court decisions interpreting the constitutional right of privacy.

### Consent for Health Care

When an adolescent seeks health care, consent for the care must be given by someone with the appropriate legal authority. Adolescents who are over the age of majority are adults and can give their own consent for health care. For an adolescent who is under the age of majority the consent of a parent or a legal guardian is generally required. However, numerous exceptions to this basic rule allow care to be provided without the consent of a parent.

Depending on the specific circumstances, consent for a minor’s care may be provided by a legal guardian, a court, or even a foster parent or other adult caretaker. Also, in emergencies, care may be provided without the prior consent of a parent, although the health care provider is usually required to inform the parent as soon as possible. In numerous instances, minors are legally allowed to give their own consent for care.

#### *Minor Consent*

The laws that authorize minors to give their own consent for health care are mostly state laws. Beginning in the middle of the 20<sup>th</sup> century, states began to enact specific statutes to enable minors to obtain care without parental consent. Over the next half century, every state enacted some of these statutes, which are generally grouped into two broad categories: laws that are based on the status of the minor and laws that are based on the type of care they are seeking.

Within each of these broad categories some of the laws contain additional variations. For example, a law may contain one or more of the following elements: an age limit, a limit on the range of specific services covered, or enumeration of the providers or sites that may deliver the care. In addition, a law may contain a statement that a physician or other health care professional may rely in good faith on representations made by the minor that he or she is legally allowed to consent. Also, a law may specify whether the parent or the minor is financially responsible for payment when the minor consents. Finally, a law may include specific provisions regarding whether information about the care for which the minor consents may be disclosed to parents or guardians.

#### *Mature Minor Doctrine*

The concept of the “mature minor” is familiar to many health care professionals who treat adolescents, but its origin and meaning are not always well understood. The mature minor doctrine developed as part of the common law in court decisions. Generally according to the

mature minor doctrine, a physician is not liable for providing care without parental consent when the care is within the mainstream of medical opinion, is not high risk, and is provided in a non-negligent manner, as long as the minor is an older adolescent who is capable of giving informed consent to the care and does consent.

The doctrine has been expressly accepted or favorably discussed by courts in several states. Many fewer states have expressly rejected the doctrine's validity. The doctrine is sometimes relied on as a justification for accepting the informed consent of mature minors for health care, even in states where courts have not expressly accepted the doctrine.

The concept of the mature minor has also been acknowledged, although without much specific definition, in U.S. Supreme Court cases ruling on requirements for parental notification or consent for a minor to obtain an abortion. It is also often mentioned in court cases addressing the right of a minor to obtain an abortion without parental consent or notification through a state's judicial bypass procedure.

Only a few states have incorporated the mature minor doctrine into a statute. A small number of states have enacted statutes that, for example, allow minors to give their own consent for care if they have "sufficient intelligence to understand and appreciate the consequences of the proposed surgical or medical treatment or procedures," using that or similar language.

#### *Consent by Minors Based on Their Status*

Every state has enacted one or more statutes allowing minors to consent for health care based on their status. The most common status categories in which states have laws expressly allowing minors to consent for health care are: emancipated minors, minors who are living apart from their parents, minors who are married, minors who are pregnant, and minors who are parents. In addition, there are other categories in which a small number of states have laws allowing minors to consent for health care such as minors who are in the military or minors who are incarcerated.

*Emancipated minors* are widely considered to have attained full or partial adult status and to be authorized to consent for their own health care. The concept of an emancipated minor originated in the common law and dates back to Colonial times. Historically, the criteria for recognizing a minor as emancipated were marriage, military service, or living apart from parents and being self-supporting. Although the concept of the emancipated minor was originally developed by the courts, numerous states have enacted statutes recognizing emancipated minors and establishing procedures for determining that a minor is emancipated. Some of the early statutes were designed primarily to allow a minor to conduct specific transactions, such as buying and selling real property or entering into contracts. Statutes enacted more recently often specify that a legally emancipated minor, who has met the statutory criteria for emancipation and received a court declaration of emancipation, may consent for health care. At least two-thirds of states have enacted statutes that expressly

authorize emancipated minors to consent for health care or specify that emancipated minors have adult status. In other states, however, minors who meet traditional criteria for emancipation should also be recognized as able to consent for health care.

*Minors who are living apart from their parents* may be expressly authorized to consent for their own health care, even if they do not meet the criteria for legal emancipation and have not received a court declaration of emancipation. Nearly one-half of states have enacted statutes that allow minors who are living apart from their parents to consent for their own health care. Some of these statutes include one or more additional specific criteria such as an age limit or a requirement that the minor be independent of parental support. However, several of the statutes also contain specific criteria designed to broaden access for these young people, such as a statement that the minor may consent regardless of the source of his or her income, regardless of the length of time he or she has lived apart from parents, or regardless of whether the young person is living apart from parents with or without parental permission.

*Minors who are married* are generally considered to be emancipated. Almost all states have enacted statutes that expressly allow married minors to consent for their own health care or specify that married minors have attained adult status. However, even in a state that has not enacted such a statute there is a strong basis for allowing married minors to consent. Marriage is one of the criteria for emancipation under both the common law and under many emancipation statutes. It would be reasonable, therefore, to consider married minors as emancipated and legally able to consent for their own health care.

*Minors who are parents* are often expressly authorized to consent for their own health care or for health care for their children. About two-thirds of states have enacted statutes that allow minors who are parents to consent for health care for themselves or their children or both. Even in the absence of a statute, minors who are parents may be able to consent for health care for themselves on some other basis: because they are emancipated, or living apart from their parents, or married, for example. Also, even in the absence of a statute, on the basis of constitutional and common law principles, minors who are parents would be able to consent for health care for their children unless they were unable to give informed consent.

Other groups of minors may be authorized to consent for health care. For example, *minors in the military* would be considered emancipated under traditional legal criteria for emancipation. Some states have enacted statutes expressly authorizing minors in the military to consent for health care. Even in the absence of such a statute, it would be reasonable to consider a minor in the military as emancipated and legally able to consent for their own health care. For states that have a statute authorizing minors in the military to consent for health care, this monograph provides that information. A small number of states have statutes that expressly authorize *minors who are incarcerated* to consent for health care.

*Consent by Minors Based on Services They Are Seeking*

Every state has enacted one or more statutes allowing minors to consent for specific types of health care. The most common categories of care for which states have laws expressly allowing minors to consent are: emergency care, general medical care, family planning services or contraceptive care, pregnancy related care, STD/VD care, reportable disease care, HIV/AIDS care, drug or alcohol care, and outpatient mental health services. Also, a small number of states allow minors to consent for other categories of services, such as care related to a sexual assault, bone marrow transplantation, or “do not resuscitate” orders.

In virtually every state, minors are able to receive *emergency care* without the prior consent of a parent. A few states expressly authorize minors to give their own consent for emergency care. At least two-thirds of states have statutes that expressly authorize minors to consent for emergency care or expressly allow care to be provided in emergencies without prior parental consent. Notice to parents as soon as possible after care has been provided is usually required. Sometimes other specific limiting criteria apply. Even in the absence of such a statute it would be reasonable to conclude that emergency care could legally be provided without prior parental consent in situations when an adolescent’s life or health is seriously endangered without the care.

Some states expressly authorize minors to consent for *general medical care*. Some of the statutes are those that are based on the status of the minor, which would only authorize minors who have attained that status to give their own consent. As discussed above, in “Consent by Minors Based on Their Status,” almost every state expressly authorizes at least some minors to consent for care based on a status such as emancipation, living apart from parents, or marriage. In addition, at least one-third of states have authorized minors to consent for health care based on their age (e.g., age 15 years) or specific criteria of maturity (e.g., have “sufficient intelligence to understand and appreciate the consequences of the proposed surgical or medical treatment or procedures”).

Numerous states expressly authorize minors to consent for *family planning services or contraceptive care*. Some of these statutes specify “family planning” or “contraceptive” services, while others specify “pregnancy related care” or services to “prevent pregnancy.” A few of the statutes include other qualifying criteria, such as a judgment by the health care professional that the minor would suffer harm without the services. About two-thirds of states have statutes that expressly authorize minors to consent for family planning services or contraceptive care. Even in the absence of such a statute, however, there may be a basis for minors to consent for family planning services or contraceptive care, based on the constitutional right of privacy or the fact that services are being provided at a site funded under the federal Title X Family Planning Program or are being paid for by Medicaid.

Whether minors may obtain *abortion services* without the consent of a parent has been the subject of extensive and repeated legislation and litigation. A large majority of states have enacted statutes requiring either parental consent or parental notification for minors to obtain

an abortion. Most of these statutes include a judicial bypass procedure, an emergency exception, and/or an exception for cases of incest or abuse. Some states allow an adult other than a parent, such as a grandmother, an aunt, or an adult sibling to provide consent or receive the required notification. Beginning in 1976, the United States Supreme Court decided a series of cases in which it held, overall, that a state may not grant an arbitrary veto to parents over the abortion decisions of their minor daughters but that under specific circumstances, requirements of parental consent or notification may be constitutional if a state also creates an alternative mechanism for a mature minor to obtain an abortion without involving a parent.

Every state allows minors to consent for *care related to sexually transmitted disease or venereal disease*. All 50 states and the District of Columbia either have a statute expressly authorizing minors to consent or specifying that minors may receive the services without parental consent (in which case, a minor would be able to give his or her own consent) or, in a very small number of states, a different type of statute (such as one addressing consent for general medical care) that allows minors to give their own consent for STD/VD care. Some of the statutes specify the scope of services (e.g., prevention, diagnosis, and/or treatment). Many of the statutes use the term venereal disease rather than sexually transmitted disease. Some states refer to a specific list of STDs or VDs.

A significant number of states expressly allow minors to consent for *care related to reportable diseases*. These statutes would cover care for reportable STD/VD, but also for other infectious, contagious, or communicable diseases. Some of the statutes specify the scope of services (e.g., prevention, diagnosis, and/or treatment). More than one-third of states have enacted such statutes. Some of the statutes specify the scope of services (e.g., prevention, diagnosis, and/or treatment).

Most states allow minors to consent for *care related to HIV/AIDS*. Some states do so in a separate statute that specifically addresses HIV and/or AIDS. Others do so through the statute that authorizes minors to consent for STD/VD care or for reportable disease care, usually by classifying HIV or AIDS as a STD or a reportable disease. Almost all states authorize minors to consent for HIV/AIDS care either directly or through one of these other laws. Some of the laws limit the type of care for which minors may consent – to testing, for example.

Almost every state allows minors to consent for *care related to use of drugs or alcohol*. Some of these statutes include limitations such as age limits or restrictions on the type of care that may be provided, such as an exclusion for methadone maintenance. Some statutes focus on either drugs or alcohol; some include both or use terminology such as substance abuse or chemical dependence.

Numerous states allow minors to consent for *outpatient mental health services*. These statutes contain a variety of limitations with respect to the age of minors who may consent, the type of care that may be provided, the health care professionals who are covered, and the number of visits for which a minor may be seen without the involvement of a parent. Nearly

two-thirds of states have enacted statutes that allow minors to consent for some outpatient mental health services. This monograph provides information for each state about whether it has enacted such a statute.

A few states allow minors to consent for other services, such as care related to *sexual assault*, or for *organ donation or transplantation*.

### Confidentiality & Disclosure

Numerous laws protect the confidentiality of health care information and specify the circumstances under which it may, may not, or must be disclosed. Many of these laws apply to adolescents who are minors as well as to adults. These laws include the constitutional right of privacy, minor consent laws, medical records and health privacy laws, evidentiary privileges, and funding statutes, among others. Particularly significant are the state minor consent laws, the HIPAA Privacy Rule, and provisions affecting Title X family planning programs and federal drug and alcohol treatment programs.

#### *Confidentiality & Disclosure Provisions of Minor Consent Laws*

In almost every state, the minor consent laws also contain one or more provisions that address the confidentiality or the disclosure of information when a minor is authorized to give consent for care. In a few states, either the minor consent laws or the medical privacy laws specify that when a minor has consented to care, information about the care may not be disclosed without the permission of the minor. In some states, a general disclosure provision applies to all of the minor consent laws; in others, a specific disclosure provision is included within one or more but not all of the minor consent laws.

Thus the disclosure provisions are not necessarily consistent among different services even within one state. Most of the disclosure provisions address the circumstances in which a health care provider may disclose information to a parent when a minor has consented to the care. These disclosure provisions are of particular importance in light of the HIPAA Privacy Rule.

#### *The HIPAA Privacy Rule*

The most important legal development in the past decade affecting the confidentiality of adolescents' health care information is embodied in the federal medical privacy regulations, the HIPAA Privacy Rule, issued under the Health Insurance Portability and Accountability Act of 1996. The Rule created new rights for individuals to have access to their protected health information and to control the disclosure of that information in some circumstances. It contains specific requirements that affect medical records and information pertaining to the care of minors. The HIPAA Privacy Rule provides that, in general, when minors legally consent to health care or can receive it without parental consent, or when a parent has assented to an agreement of confidentiality between the minor and the health care provider, the parent does

not necessarily have the right to access the minor's health information. Whether a parent may do so depends upon "state or other applicable law."

Thus, a health care provider must look to state laws or other laws to determine whether they specifically address the confidentiality of a minor's health information. State or other laws that explicitly require, permit, or prohibit disclosure of information to a parent are controlling. If state or other laws are silent on the question of parents' access, a health care professional exercising professional judgment has discretion to determine whether or not to grant access.

The relevant sources of state or other law that a health care provider must consider include state minor consent laws, state medical privacy laws, the federal confidentiality rules for the federal Title X family planning program, the federal confidentiality rules for drug or alcohol programs, and court cases interpreting both these laws and the constitutional right of privacy. In at least some states, statutes enacted at the state level to implement the HIPAA Privacy Rule explicitly incorporate protections for adolescents who are minors, in others they do not.

*Special Considerations for Family Planning, Contraception, & Pregnancy Related Care*

Special considerations pertain to consent and confidentiality questions related to family planning, contraception, and pregnancy related care for minors. The most important considerations pertain to court decisions based on the constitutional right of privacy and the confidentiality requirements that are part of the federal Title X family planning program and Medicaid.

The U.S. Supreme Court has held that the constitutional right of privacy extends to minors as well as adults and that it encompasses minors' reproductive decisions. The Supreme Court has also explicitly recognized that minors' access to contraceptives falls within the ambit of the constitutional right of privacy. Moreover, courts have not found that parental consent for minors to obtain contraceptives is required and have struck down statutes that attempted to require parental consent for contraceptives in several cases. Therefore, even in the absence of a statute authorizing minors to consent for family planning services or contraceptive care, if there is no valid statute or case prohibiting them from doing so, it would be reasonable to conclude that minors may give their own consent for these services.

In every state, at sites that receive funds under the federal Title X Family Planning Program, minors are legally able to obtain family planning services and contraceptive care without parental consent or notification. Title X specifies that family planning services must be available without regard to age and includes detailed confidentiality rules. Title X encourages, but does not require, family participation. The Medicaid program also requires that confidential family planning services be available to adolescents as well as adults who are eligible for Medicaid.

*Special Considerations for Drug and Alcohol Care*

Detailed federal confidentiality regulations apply to facilities that meet a definition of federal drug or alcohol treatment programs. These rules do not contain provisions that determine whether or not a minor may consent to services in the programs. However, they do provide that if a minor is allowed to consent to services under state law, specific confidentiality protections contained in the federal rules apply. Almost every state allows minors to give their own consent for drug or alcohol care. In some states, the minor consent laws also contain confidentiality or disclosure provisions. For example, some state laws authorizing minors to consent for care related to drug or alcohol problems also provide that parents should be given information about the care. Such provisions must be analyzed in light of the federal drug and alcohol confidentiality rules to determine whether they are valid. Special care must be taken to understand the relationship between these laws and the federal drug and alcohol confidentiality rules.

Questions and Challenges for the Future

At least two significant developments are taking place currently that raise significant questions and challenges with respect to protecting the confidentiality of sensitive information in the medical records of adolescents. One of these developments is the expansion of coverage to new individuals and additional services through health care reform. The other is the expansion of health information technology and the implementation of electronic medical records.

In the past, adolescents and young adults have been uninsured at disproportionately high rates. However, over the past decade or so, more adolescents have received health insurance through Medicaid and CHIP. Now, with the enactment of national health care reform and other health care reform initiatives at the state level, the proportion of adolescents and young adults who have public or private health insurance will increase even further. Moreover, health insurance coverage for some important benefits, such as preventive services, will also be expanded. This welcome development creates some new challenges for protecting sensitive health information. For example, as young adults are able to remain on their parents health insurance until age 26, their need to receive certain services (e.g., STI testing) on a confidential basis may conflict with requirements that policyholders receive explanations of benefits and other documentation of care provided. Finding ways to enable adolescents and young adults who have health insurance coverage to receive confidential services without having to forego the benefits of using their health insurance coverage to pay for the care is an important challenge.

Similarly significant challenges exist with respect to the implementation of electronic medical records. Although the range of services for which adolescents may need confidentiality protection does not change because medical records are maintained in electronic form, the need to develop effective mechanisms for protecting the confidentiality of sensitive information requires addressing not only the complexity of the legal framework that applies to consent and

confidentiality in adolescent health care, but also the technically complex questions of how to allow parents access to the information for which they have both a legitimate need and a legal right, while also protecting the rights of adolescents to receive confidential services when necessary to ensure that they receive essential care. Solutions to these challenges should not result either in unduly restricted access to information by parents or adolescents or to unlimited access to information that should be protected for legal and ethical reasons and to promote the public health.

I thank you once again for the opportunity to present this testimony and I would be happy to respond to any questions you may have.

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