This second edition of *Policy Compendium on Confidential Health Services for Adolescents* represents a collaborative effort between the Center for Adolescent Health & the Law, the American Medical Association (AMA), and members of the AMA National Coalition on Adolescent Health and the AMA Educational Forum on Adolescent Health.

The first edition of this Compendium was published in 1993 by the American Medical Association and contained policies that were current as of August 1, 1992. Recognizing that the original edition has played a critical role in educating both health care providers and policy makers about the need for confidential health services for adolescents, the Center for Adolescent Health & the Law and the AMA sought to revise the Compendium to reflect the organizational policies that have been adopted during the past decade and to present those in the context of the current legal, policy, and health care environment.

The Center for Adolescent Health & the Law is a national nonprofit organization that supports laws and policies that promote the health of adolescents and their access to comprehensive health care. The American Medical Association created the AMA National Coalition on Adolescent Health in 1987 and, in 2002, convened a complementary group, the AMA Educational Forum on Adolescent Health. Together, the AMA Coalition and Forum include more than 25 organizations whose members provide direct health care services to adolescents.

During 2002 and 2003, the Center for Adolescent Health & the Law contacted the national health care provider organizations that participate in the AMA National Coalition on Adolescent Health or the AMA Educational Forum on Adolescent Health to solicit their input to this Compendium. The following organizations provided documents that are cited in this Compendium:

- American Academy of Child & Adolescent Psychiatry (AACAP)
- American Academy of Family Physicians (AAFP)
- American Academy of Pediatric Dentistry (AAPD)
- American Academy of Pediatrics (AAP)
- American College of Emergency Physicians (ACEP)
- American College Health Association (ACHA)
- American College of Obstetricians and Gynecologists (ACOG)
- American College of Physicians (ACP)
- American College of Preventive Medicine (ACPM)
- American Medical Association (AMA)
- American Nurses Association (ANA)
- American Psychiatric Association (APA)
- American Psychological Association (APA)
- American Public Health Association (APHA)
- American School Health Association (ASHA)
- National Assembly on School-Based Health Care (NASBHC)
- National Association of Pediatric Nurse Practitioners (NAPNAP)
- National Association of School Psychologists (NASP)
- National Association of Social Workers (NASW)
- Society for Adolescent Medicine (SAM)

Because organizational policy can be reflected in a variety of formally-endorsed documents, the data sources for this Compendium include a number of materials, including:

- position statements;
- resolutions;
- position or policy papers;
- comments submitted in response to proposed regulations (particularly related to the HIPAA medical privacy regulations);

- testimony or letters submitted to Congress or the Administration;
- codes or principles of ethics; and
- other formal organizational practice guidelines.

In some cases, these documents are available in published journals or on the organizations' websites. To ensure that the data collection process yielded both comprehensive and accurate results, individuals representing the organizations included in this Compendium were asked to review the draft, provide copies of any relevant policies that had not been identified in the preliminary data collection phase, and confirm that the policies quoted herein reflect the current policies of their organization.

These formal policy documents were analyzed to identify a range of themes such as the rationale for supporting confidential health care for the general population and for adolescents in particular; policies and procedures to protect confidentiality; the roles of parents and guardians in adolescent health care; the importance of informing adolescents and parents about confidentiality protections and limitations to those protections; policies about informed consent and confidentiality for specific health services; confidentiality concerns for particular populations of adolescents; and statements about confidentiality in particular health care settings. The text and tables of this Compendium have been organized according to these themes.

The text for this Compendium has been taken verbatim from the organizations' policy documents. At times, punctuation has been edited or citation numbers from the original text have been deleted to improve readability. Within each section of this Compendium, policy statements are presented in alphabetical order by organization. Where applicable, policy statements that have been endorsed by more than one organization are presented at the beginning of the section. When text from a particular statement is applicable to more than one section, it has been repeated.

While this Compendium represents a broad range of policies with respect to confidential health services for adolescents, its scope is, nonetheless, limited. For example, this Compendium does not address policies related to genetic testing, health education or sexuality education provided outside of context of confidential health care delivery, adolescents' participation in research, or the myriad ethical and legal requirements for confidentiality and reporting of child abuse.

As with the original document, this second edition of *Policy Compendium on Confidential Health Services for Adolescents* is intended for a diverse group of professionals who work with or on behalf of adolescents. Its goals are:

1) To educate health care professionals and policy makers about the essential role that confidential services play in adolescents' access to health care;

2) To encourage organizations to develop or clarify policy recommendations about confidentiality which address the unique developmental and health care needs of adolescents and to educate their membership about their policies; and

3) To serve as a resource for individuals and organizations working to ensure that public policy supports adolescents' access to confidential health services.

Importance of Confidentiality for Adolescents [a]

For the past several decades, public policy, laws, and professional guidelines have recognized that some adolescents would forego or delay seeking needed health care if they could not receive confidential care and that this result would lead to negative health outcomes both for individual adolescents and the health of the public in general. [b, c] This recognition is well grounded in what research findings have told us about the importance of confidentiality to adolescents.

Research studies spanning more than 30 years have provided insight into the extent to which confidentiality is important to adolescents and the reasons why that is true. Findings from the 1970s and early 1980s have been confirmed in more recent studies. Collectively, these findings demonstrate that adolescents' privacy concerns affect their access to and use of many different types of health services. Particular concerns are related to sexual activity, pregnancy, sexually transmitted infections (STIs), HIV, substance abuse, and mental health.

Evidence gained from research confirms that concerns about privacy can act as a significant barrier to adolescents seeking health care. [d, e, f, g, h, i, j] This has been documented in both large nationally representative surveys and smaller state or local studies. In one national survey, 35 percent of middle and high school students who reported that they did not seek health care they needed cited one of their reasons as "not wanting to tell their parents." [e]

The impact of privacy concerns on whether adolescents seek care for specific sensitive health concerns appears to be even higher. In a recent survey in one state, 59 percent of single, sexually active girls under age 18 who were using family planning clinics indicated they would stop using *all* sexual health services, discontinue use of *specific* sexual health services, or delay testing or treatment for HIV or other STIs, if their parents were informed that they were seeking prescribed contraceptives. [g] Moreover, in a subsample of this study, of the adolescent girls who indicated they would stop using family planning services if their parents were informed of their use of contraceptive services, only one percent reported that they also would stop having sexual intercourse; instead, the vast majority reported that they would continue to have sex, but use less effective contraceptive methods or none at all. [g]

Recent research also has confirmed that privacy concerns influence adolescents' choice of health care provider or site, [h, k] the degree to which they communicate openly with health care providers, [l] and their willingness to accept services such as pelvic examinations and testing for STIs or HIV. [m, n, o]

Ultimately, when adolescents are discouraged from seeking health care due to concerns that the care will not be confidential, the result can lead to adverse health outcomes. Further research is needed on the magnitude of this effect, but at least two recent studies have measured the potential increase in pregnancies and STIs, with the likelihood of significant increases in public financial costs, when this occurs. [p, q]

The Legal Framework for Confidentiality in Adolescent Health Care

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 legislatures, regulations promulgated by administrative agencies, and cases decided by courts. Statutes known as "state minor consent laws" are particularly notable for their role in determining the consent requirements for adolescents to receive health care. [r] At the federal level, the new federal medical privacy regulations known as the "HIPAA Privacy Rule" are of similar importance for the confidentiality of adolescents' health information. [c, s] Many other laws have great 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.

Many of the laws that protect the confidentiality of health care information apply to adolescents who are minors as well as to adults. [t] They include the constitutional right of privacy, minor consent laws, medical records and health privacy laws, evidentiary privileges, and funding statutes, among others. Most significant for this Compendium are

the state minor consent laws, the HIPAA Privacy Rule, and provisions affecting the federal Title X Family Planning Program and federal drug and alcohol treatment programs.

Confidentiality & Disclosure Provisions of Minor Consent Laws

In almost every state, the minor consent laws contain one or more provision that addresses the confidentiality or the disclosure of information when a minor may 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. [r] (State-specific information about state minor consent laws may be found in English and Kenney, 2003. [r])

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. [r] Thus the disclosure provisions are not necessarily consistent among different services even within one state. Most of the disclosure provisions that are included 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 recent development affecting the confidentiality of adolescents' health care information is embodied in federal medical privacy regulations, the HIPAA Privacy Rule, issued under the Health Insurance Portability and Accountability Act of 1996. The rule creates 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. [u]

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 the parent may do so is dependant 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 in relation to parents' access to information. 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.

Under HIPAA, 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 to a minor's health information, a health care professional exercising professional judgment has discretion* to determine whether or not to grant access. The deference to professional judgment in the HIPAA Privacy Rule, when state and other laws are silent on the question of parents' access to information, underscores the importance of the confidentiality policies contained in this Compendium.

Taken separately and together, these policy statements can provide important guidance and support to health care professionals when they are called upon to make discretionary determinations about whether to disclose confidential information about adolescents. These policy statements also can provide support for health care professionals who are working within their own institutions and health care sites to develop appropriate guidelines to help in making these determinations.

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. Most importantly, these include 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. [v, w]

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. [x, y] The Supreme Court also has explicitly recognized that minors' access to contraceptives falls within the realm protected by the constitutional right of privacy. [y] Moreover, courts have not found that parental involvement for minors to obtain contraceptives is required and have struck down statutes that attempted to require parental consent or notification for contraceptives in several cases. [z, aa]

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. [v] 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. [w]

Special Considerations for Drug and Alcohol Care

A set of detailed federal confidentiality regulations is applicable to facilities that meet a definition of federal drug or alcohol treatment programs. [bb] 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 from the federal rules apply. Almost every state allows minors to give their own consent for drug or alcohol care. [r] In some states, the minor consent laws also contain confidentiality or disclosure provisions. Special care must be taken to understand the relationship between these laws and the federal drug and alcohol confidentiality rules.

Ethical Framework for Confidentiality in Adolescent Health Care

In addition to the legal underpinnings, there is a strong ethical foundation for providing confidentiality protections in adolescent health care. [cc] Protecting the confidentiality of adolescents' health information is a professional duty that derives from the moral tradition of physicians and the goals of medicine and that is well established as a duty for most health care professionals. Ethical principles of autonomy, nonmaleficence, beneficence, and justice are all key elements of the ethical framework for confidentiality in adolescent health care. Many of the organizations whose policies are represented in this Compendium have adopted ethical codes, ethical principles, or ethics manuals. These often embody the ethical bases for providing adolescents with confidentiality protection.

Confidentiality Challenges in Clinical Settings and Financing Systems

Many practical issues affect a clinician's ability to provide confidential care for adolescents. Clinicians must determine minors' capacity to give informed consent. They need to understand and screen for situations that will limit their ability to provide minors with confidential care, such as suspected physical or sexual abuse and risk of homicide or suicide. Clinicians also face challenges concerning how to maintain their records when the parent has rights to obtain some—but not all—of their adolescents' health information. Electronic medical records, over which physicians may have little control, add further complexity to this issue. [c]

Third party reimbursement creates additional challenges. Many adolescents are covered either by public or private insurance, but some are unwilling or unable to use their insurance coverage for contraceptive services, diagnosis and treatment of STIs, or other sensitive issues, because they worry that their parents will be notified through the billing and insurance claims process, despite the fact that minor consent laws may permit them to seek these services without parental consent. The legal rules for integrating confidential care for adolescents with a complex system of third party reimbursement is still very much in evolution. Effective implementation of confidentiality protections for adolescents in the third party payer arena will require the willing and active cooperation of both health care providers and third party payers. [c]

Finally, clinicians face the challenge of conveying the protections and limitations of confidentiality to adolescent patients and their parents. They also face the challenge of encouraging communication between adolescent patients and their parents in a way that is respectful of adolescent's need for privacy and the support that parents can provide. [c]

Ensuring access to confidential health care for adolescents involves significant challenges from the perspectives of clinical decision making and counseling, information systems, and reimbursement mechanisms. The policies contained in this Compendium provide significant guidance on many of these issues.

References

a. This introduction was written by Abigail English, JD, Director, Center for Adolescent Health & the Law. Brief portions of this introduction originally appeared in English A, Kenney, KE. State Minor Consent Laws: A Summary, 2nd Edition. Chapel Hill, NC: Center for Adolescent Health & the Law, 2003 and in English A, Ford CA. The HIPAA Privacy Rule and adolescents: Legal questions and clinical challenges. Perspectives on Sexual and Reproductive Health 2004;36:80-86 and are used here with permission.

b. Ford CA and English A. Limiting confidentiality of adolescent health services: What are the risks? JAMA 2002;288(6):752-753.

c. English A, Ford CA. The HIPAA Privacy Rule and adolescents: Legal questions and clinical challenges. Perspectives on Sexual and Reproductive Health 2004;36:80-86.

d. Klein J, McNulty L, Flatau C. Teenager's self-reported use of services and perceived access to confidential care. Arch Pediatr Adolesc Med 1998;152:676-682.

e. Klein J, Wilson K, McNulty M et al. Access to medical care for adolescents: Results from the 1997 Commonwealth Fund Survey of the Health of Adolescent Girls. J Adolesc Health 1999;25:120-130.

f. Ford C, Bearman P, Moody J. Foregone Health Care Among Adolescents. JAMA 1999;282:2227-2234.

g. Reddy DM, Fleming R, Swain C. Effect of mandatory parental notification on adolescent girls' use of sexual health care services. JAMA 2002;288:710-714.

h. Sugerman S, Halfon N, Fink A et al. Family planning clinic clients: Their usual health care providers, insurance status, and implications for managed care. J Adolesc Health 2000;27:25-33.

i. Marks A, Malizio J, Hoch J et al. Assessment of health needs and willingness to utilize health care resources of adolescents in a suburban population. J Peds 1983;102(3):456-460.

j. Cheng T, Savageau J, Sattler A et al. Confidentiality in health care: A survey of knowledge, perceptions, and attitudes among high school students. JAMA 1993;269(11):1404-1407.

k. Lane M, McBright J, Garrett K et al. Features of sexually transmitted disease services important to African-American adolescents. Arch Pediatr Adolesc Med 1999;153:829-833.

l. Ford C, Millstein S, Halpern-Felsher B et al. Influence of physician confidentiality assurances on adolescents' willingness to disclose information and seek future health care. JAMA 1997;278(12):1029-1034.

m. Thrall J, McCloskey L, Ettner S et al. Confidentiality and adolescents' use of providers for health information and for pelvic exams. Arch Pediatr Adolesc Med 2000;154:885-892.

n. Ford CA, Best DB, Miller WC. Confidentiality and adolescents' willingness to consent to STD testing. Arch Pediatr Adolesc Med 2001;155:1072-73.

o. Meehan TM, Hansen H, Klein WC. The impact of parental consent on the HIV testing of minors. AJPH 1997;97:1338-1341.

p. Franzini, L, Marks, E, Cromwell, PF et al. Economic costs due to health consequences of teens' loss of confidentiality in obtaining reproductive health care services in Texas. Arch Pediatr Adolesc Med 2004;158:1140-1146.

q. Zavodny M. Fertility and parental consent for minors to receive contraceptives. AJPH 2004;94:1347-1351.

References

r. English A, Kenney, KE. State Minor Consent Laws: A Summary, 2nd Edition. Chapel Hill, NC: Center for Adolescent Health & the Law, 2003.

s. Standards for Privacy of Individually Identifiable Health Information, 45 C.F.R. Parts 160 and 164. Final Rule, 65 Federal Register 82461 (Dec. 28, 2000); Final Rule, 67 Federal Register 53182 (Aug. 14, 2002).

t. The term "minor" refers to an individual who has not reached the age of "majority" or adulthood as defined by state law. In most states, the age of majority is 18. (See reference r.)

u. Appendix C of this Compendium provides additional background information about the significance of the HIPAA Privacy Rule for adolescents.

v. 42 U.S.C. §§ 300 et seq. 42 C.F.R. Part 59.

w. 42 U.S.C. §§ 1396a(a)(7), 1396d(a)(4)(C). 42 C.F.R. § 441.20.

x. Planned Parenthood of Central Missouri v. Danforth, 428 U.S. 52 (1979).

y. Carey v. Population Services International, 531 U.S. 678 (1977).

z. T.H. v. Jones, 425 F. Supp. 873 (D. Utah), aff'd in part 425 U.S. 986 (1976).

aa. Planned Parenthood Federation of New York v. Heckler, 712 F. 2d 650 (D.C. Cir. 1983); National Family Planning and Reproductive Health Association v. Department of Health and Human Services, F. 2d 650 (D.C. Cir. 1983.

bb. 42 C.F.R. §§ 2.11 et seq.

cc. Society for Adolescent Medicine. Confidential health care for adolescents: Position paper of the Society for Adolescent Medicine. J Adolesc Health 2004;35:160-167.