CONSENT AND CONFIDENTIALITY IN ADOLESCENT HEALTH CARE DECISIONMAKING

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CONSENT AND CONFIDENTIALITY IN ADOLESCENT HEALTH CARE DECISIONMAKING¹

Introduction

Who should decide whether an adolescent is provided health services, what health services are provided, and how health services are provided? The adolescent? The adolescent's parents or legal guardian? Health professionals? The state? And who should decide whether adolescents' communications with health professionals and health care records are to be treated as confidential?

The question of how authority for adolescent health care decisionmaking should be allocated has been much debated—and is far from being settled. The body of law that determines how this authority is allocated-including the extent of parental involvement in adolescent health care decisionmaking—is summarized in this chapter. That body of law is large and complicated and is not always clear or consistent, in part because it is an amalgam of decisions of State and Federal courts, statutes passed by Congress and State legislatures, and regulations issued by executive departments and agencies.

The common law rule-to which there are many notable exceptions identified in this chapter—is that parental consent is generally required for the medical or surgical care of a minor child (i.e., a son or daughter who has not reached the age of majority, either age 18 or 19, depending on the State). The rationales for parental consent requirements are several. One rationale is that minors lack the capacity to make their own health care decisions and need to be protected from their own improvident decisionmaking. The legal presumption that minors are incompetent rests at least in part on an assumption of courts and legislators that minors as a class lack the requisite capacity to make health care decisions for themselves. Recently, the factual validity of that assumption has been increasingly criticized on the ground that it inequitably denies minors in middle or late adolescence-many or most of whom may actually have the requisite decisionmaking capacity-the power to make their own decisions about services. Several empirical studies that challenge the legal presumption about the incompetency of minors to make health care decisions are summarized in the second part of this chapter.

It is important to recognize, however, that concerns about adolescents' competency to make decisions are not the only rationale for parental consent requirements. Several other rationales for such requirements are reviewed in the discussion that follows, among them the state's interest and families' interest in encouraging family involvement in minors' lives and health care providers' interest in being able to receive compensation for the services they provide to minors.

How the law should allocate authority for making decisions about adolescent health care has traditionally been a matter for the individual State governments to determine, but the allocation of authority is or can be controlled or influenced to some extent by the Federal Government acting through the Federal courts, Congress, and Federal agencies. If it chose to, Congress could increase the Federal Government's role in the formulation of more uniform or coherent policies pertaining to the allocation of authority for adolescent health care decisionmaking. That and other possibilities are discussed, and a conceptual framework for public policy formulation in allocating authority for adolescent health care decisionmaking is presented, in the concluding section of this chapter.

Law Pertaining to Consent and Confidentiality in Adolescent Health Care Decisions

The large and complicated body of law that determines the allocation of authority for adolescent

¹This chapter is based on a February 1990 background PaPer entitled "Adolescent Health Care Decisionmaking: The Law and Public Policy," prepared for OTA's Adolescent Health Project under contract to the Carnegie Council on Adolescent Development by J. Gittler, M. Quigley-Rick, and M.J. Saks. That background paper has been published separately in its entirety, including extensive legal citations, and is available from the Carnegie Council on Adolescent Development, Washington, DC, or from OTA.

health care decisionmaking is summarized below.² Much of the law focuses on the nature and extent of parental involvement in adolescent health care decisionmaking, including whether an adolescent's parents must *consent* to the delivery of health services to the adolescent and whether an adolescent's parent must be *notified* of the adolescent's decision to obtain health services or of the adolescent's actual receipt of health services.

As noted in the introduction, the body of law that determines the allocation of authority for adolescent health care decisionmaking is not always clear or consistent, in part because it is an amalgam of principles and rules drawn from different areas of law (e.g., tort law, contract law, family law, and constitutional law) and different jurisdictions, and in part because it consists of decisions of Federal and State courts, statutes passed by Congress and State legislatures, and regulations issued by executive departments and agencies. For at least some adolescents, a lack of information about what services they can or cannot receive without parental consent or notification may be a barrier to their seeking or receiving certain types of health services. For other adolescents, the barrier may be the substance of the laws requiring parental consent or notification rather than confusion about what the law allows.

Parental Consent Requirements

Anglo-American law draws a sharp distinction between adults and minors, and it is well established that minors have fewer rights and more restrictions on their liberty than adults (27,33). It is also well established that parents have a right to care, custody, and control of their minor children (83). Perhaps not surprisingly, therefore, the common law rule is that parental consent is generally required for the medical or surgical care of a minor child. The age of majority is determined by individual States. Currently, the age of majority is set at age 18 in every

State but Alaska, Nebraska, and Wyoming, where the age is 19. States can modify the age of majority to confer upon minors rights normally reserved for adults, and five States (Alabama, Kansas, Rhode Island, South Carolina, and Oregon⁴) have enacted statutes that specifically authorize minors who have reached a designated age—ranging from 14 to 16---to consent to health care.

The parental consent requirement reflects the application to minors of the tort law doctrine of informed consent, as well as principles under contract law. As discussed later in this chapter, the legal doctrine of informed consent is based on the premise that every person has the right to determine what is done to his or her own body. The doctrine of informed consent holds, therefore, that physicians and surgeons have a duty to give their adult patients the information necessary for making an informed and voluntary choice concerning medical treatment or surgery; the failure by a physician or surgeon to obtain informed consent from a patient may give rise to a civil liability and an award of damages. In addition, under contract law, the relationship between a doctor and an adult patient is usually considered a contractual relationship. Among the essentials of any contract are competent parties.

Traditionally, minors have been deemed incompetent as a matter of law to give informed consent to medical and surgical care and incompetent to enter into binding contracts, including contracts with physicians and surgeons. Thus, parental consent has been required for provision of health services to minors.

The rationales for parental consent requirements in the area of health care are several. One of the main rationales for the parental consent requirement—based on the assumption that minors lack the requisite capacity to make health care decisions—is the need to protect minors from their own improvi-

²Although the focus of this OTA Report is on "adolescents" defined as individuals ages 10 to 18, the law regards 10- to 18-year-olds not as "adolescents" but as either "minors" or "adults." Since 18-year-olds are legally considered adults in all but three States, most of the issues about adolescent health care decisionmaking raised in this chapter pertain to adolescents ages 17 and under.

³See, for example, Bonner v. Moran, 75 App. D.C. 156, 126 F.2d 121, 123 (D.C. Cir. 1941); Rogers v. Sells, 178 Okla. 103,61 P.2d1018 (1936); Browning v. Hogan, 90 W. Va 568, 111 S.E. 492 (1922). See Institute of Judicial Administration and American Bar Association, Juvenile Justice Standards Project, Standards Relating to Rights of Minors (47); G.D. Dodson, "Legal Rights of Adolescents: Restrictions on Liberty, Emancipation% and Status Offenses" (33); and R. Bennett, "Allocation of Child Medical Care Decision-Making Authority: A Suggested Interest Analysis" (19).

⁴ALA.CODE § 22-8-4 (1984); KAN.STAT.ANN. § 38-123b (1986); R.I.GEN.LAWS § 23-4. 6- I (1985); S.C. CODE ANN. § 20-7-280 (Law. Co-op. 1985); OR. REV. STAT. \$109.640 (1981).

⁵The law of torts protects persons against unauthorized bodily invasion. Bodity contact with a patient by a physician or surgeon without the Patient's consent constitutes technical battery, which is a tort (53).

dent decisionmaking. 6 Accepting for the sake of argument that minors in fact need protection from their own improvident decisionmaking, there remains the question of why parents have been legally authorized to make health care decisions on behalf of their minor children. There appear to be two operative premises in this regard: 1) that parents, in contrast to their minor children, possess the intelligence, maturity, and experience needed for adequate and appropriate health care decisionmaking; and 2) that parents usually have an identity of interest with their minor children and will act in their best interests. In at least some situations, parents and their adolescent children do not have an identity of interest, and sometimes their interests may conflict. It is precisely such situations that give rise to concerns that parental consent or notification requirements may create barriers to adolescents' seeking or receiving certain types of health services.

Another rationale for the parental consent requirement—apart from the need to protect minors from their own improvident decisionmaking--is a belief that the parental consent requirement promotes family autonomy⁸ and privacy and promotes parental authority⁹ and control of minor children. Family autonomy and parental authority, in turn, are often viewed as fostering the stability and cohesiveness of

the family as an institution and of individual family units. The U.S. Supreme Court has commented in a series of decisions on the importance of family autonomy and parental authority, and the Court has extended Federal constitutional protection, albeit not absolute protection, to family autonomy and parental authority .10 The parental consent requirement also seems, at least somewhat, to be designed to protect parents from financial liability arising from the provision of health services, without their consent, to their children and to ensure providers of the availability of a payment source for the services they provide to minors.

Exceptions to the Parental Consent Requirement

Over the years, the number of exceptions to the parental consent requirement applicable to the health care of minors has grown significantly. Exceptions to the parental consent requirement, described below, tend to fall into four categories:

- exceptions arising out of the jurisdiction of juvenile and family courts over abused and neglected minors,
- . exceptions related to the status and characteristics of individual minors (e.g., emancipated, independent, or mature minors),

6In dealing with issues of consent to health care for minors, State courts and lower Federal courts have consistently expressed concern about the decisionmaking capabilities of minors. In *Bonner* v. *Moran*, 75 App. D.C. 156, 126 F.2d 121, 122 (1941), for example, the court stated: "In deference to common experience, there is general recognition of the fact that many persons by reason of their youth are incapable of intelligent decisions, as a result of which public policy demands legal protection of their personal as well as their property rights. 'In recent yearn, the U.S. Supreme Court, in dealing with issues concerning access of minors to contraceptives and abortions and the civil commitment of minors, has similarly expressed concern about the decisionmaking capabilities of minors. For example, in *Parhamv.J.R.*, 442 U.S. 584, 602, 603 (1978), the court stated: "Most children, even in adolescence, simply are not able to make sound decisions, including their need for medical care or treatment.' See also *Bellotti v. Baird*, 443 U.S. 622, 633,640 (1978), reh. denied, 444 U.S. 887 (1979); *Planned Parenthood of Missouri v. Danforth*, 428 U.S. 52,91 (1976) (Stewart, J., concurring); *Carey v. Population Services International*, 431 U.S. 678,709 (1977) (Powell, J. concurring); Carey v. *Population Services international*, supra at 714 (1977) (Stevens, J. concurring).

⁷For a further discussion of how the interests of an adolescent, the adolescent's parents, the state, and health providers may differ, see box 17-B in the concluding section of this chapter.

**Family autonomy refers t. noninterference by the state in the right of families to make important decisions concerning family life and family members. A tradition of family autonomy is deeply imbedded in Anglo-American law and can be traced back to Roman law, the JudeO-Christian tradition, and Anglo-Saxon customary law. Family autonomy is often but not always equated with parental authority (42).

9Parental authority refers t. the deference of the state t. the right of parents to make childrearing decisions (42). At common law, minor children were in effect the chattels or property of their parent, who had virtually the unfettered right to rear them as they saw fit. Over time, minor children increasingly have been recognized as having independent rights (45), yet they are still largely subject to the authority of their parents.

to line of decisions over 50 years, the U.S. Supreme Court has held that parents have a Federal constitutional right to direct the upbringing of their children free from state intervention in the absence of a constitutionally acceptable justification for such intervention. The Court's most notable decisions in this regard are Meyer v. Nebraska, 262 U.S. 390 (1923); Pierce v. Society of Sisters, 268 U.S. 510 (1925); Prince v. Massachusetts, 321 U.S. 158 (1944); and Wisconsin v. Yoder 406 U.S. 205 (1972). See also Ginsburg v. New York 390 U.S. 629,634 (1968), reh. denied, 391 U.S. 971 (1973). In another line of decisions, the U.S. Supreme Court has afforded minors some of the same constitutional rights that adults are afforded areas that do not directly implicate parents' right to direct the upbringing of their children. See, for example, InreGault, 387 U.S. 1 (1967); Tinker v. Des Moines Independent Community School District, 393 U.S. 503 (1969); and Goss v. Lopez, 419 U.S., 565 (1975). In recent years, the U.S. Supreme Court has begun to confront conflicts between a parent's asserted right to direct the upbringing of his or her minor child and the minor's assertion of his or her own independent rights and has issued several decisions involving actual or potential parent-child conflicts with respect to the access of minors to contraceptives and abortions and the civil commitment of minors. Taken as a whole, however, the results and rationales of the Supreme Court's decisions do not reflect a coherent approach to such conflicts.

- . exceptions for health emergencies, and
- * exceptions for specific health problems and services (e.g., services related to sexual activities, drug and alcohol abuse, or mental health).

As noted in the discussion that follows, some of the exceptions apply to certain categories of minors regardless of their age, and others are directed at or affect primarily adolescent minors. For a number of exceptions to parental consent requirements for specific health problems, as will be discussed later, there are now in place parental notification requirements.

Exceptions Arising From Juvenile and Family Courts' Jurisdiction Over Abused and Neglected Minors

In all States, juvenile and family courts have jurisdiction over minors of all ages who have been abused or neglected. Exercising this jurisdiction, juvenile and family courts have traditionally had the power to intervene to secure health services for minors whose parents refuse to consent to the provision of services if the parents' refusal is deemed medical neglect. The basis for judicial intervention under State juvenile and family court acts in such instances is the state's parens patriae power. In many instances where medical neglect is alleged, the parents' refusal to consent to care is based on religious convictions. Judicial intervention typically occurs only when a minor's life is or will be threatened because of lack of care.

Exceptions Related to the Status and Characteristics of Individual Minors

Two major types of exceptions to the parental consent requirement are related to the status and characteristics of individual minors:

- . exceptions for "emancipated minors and "independent minors, and
- exceptions for "mature minors.

Exceptions for "Emancipated" and "Independent" Minors-Emancipation is a somewhat murky and confused area of the law, but generally speaking, "emancipated minors are minors who have been legally freed from the control and authority of their parents. Under the common law doctrine of emancipation, courts-without explicit

statutory authorization-may use various factors in determining whether a minor's emancipation has taken place. Emancipation may be found to have occurred in accordance with an express agreement between a minor's parents and the minor or may be implied from the acts of the minor's parents and the minor. The main indicia of emancipation implied from the acts of the parties are a minor's marriage, a minor's induction into the armed services, a minor's establishment of a home away from that of his or her parents, a minors' economic independence from his or her parents, and a minor's age (50). Emancipation under common law may be complete or partial and may or may not result in a minor's having the right to consent to health services.

About half of the States have enacted statutes that provide for court-ordered emancipation of minors or specify that certain designated acts by a minor's parents, a minor, or both constitute emancipation. Some of these statutes explicitly state that emancipation under these statutes removes the disabilities of minority, including the requirement of parental consent to health services. Thus, minors emancipated under these statutes have the right to consent to health services.

A substantial number of States have enacted statutes that authorize minors who have attained varying degrees of *independence* to consent to health services but that do not use the term 'emancipation' or "emancipated' minors. Over half of the States have "independent minor' statutes that allow minors who are parents to consent to health care for themselves and/or their children; about half of the States have statutes that allow married minors to consent to health care; and some States have statutes that allow independent minors in other categories (e.g., minors living apart from their parents and managing their own financial affairs, minors in the military, minors who are high school graduates) to consent to health services.

Emancipated minor and independent minor exceptions to the parental consent requirement affect minors who have achieved complete or substantial independence from their parents, so they primarily affect adolescent minors. The focus of these exceptions is the minor's independence, not the minor's capacity to make health care decisions. These

¹ I For discussions of the origins and development of emancipation, see H.H. Clark, *The Law of Domestic Relations in the United States* (27); F. Cady, "Emancipation of Minors" (24); and S. Katz, W. Schroeder, and L. Sidman, "Emancipating Our Children-Corning of Age in Legal America" (50).

exceptions seem to reflect legislative judgments that a minor who is not part of a functioning family, or whose parents exercise little or no control over him or her, is in a better position to make health care decisions than the minor's parents.

Exceptions for "Mature" Minors-The "mature minor" exception to the parental consent requirement has been enunciated primarily by courts rather than by State legislatures. This exception was recognized by State courts beginning in the early 1900s. According to one authority, the factors supporting a determination of a minor's maturity for purposes of health care decisionmaking in these decisions are as follows:

(1) the treatment is undertaken for the benefit of a minor rather than a third party; (2) the particular minor is near the age of majority; (3) the minor is considered to have sufficient mental capacity to understand fully the nature and importance of medical steps proposed; (4) the procedures are characterized as less than major, 'not serious' or not overly 'complex' (75).

Recently, the mature minor doctrine has been applied by the U.S. Supreme Court in decisions dealing with the right of a minor to family planning services and abortion services (see discussion below). Only a few States have mature minor statutes. Three States (Arkansas, Mississippi, and New Hampshire¹²) have enacted statutes that explicitly authorize mature minors to consent to health services, and two States (Idaho and Nevada¹³) have enacted statutes that are somewhat ambiguous but could be construed to constitute mature minor consent statutes.

The mature minor exception to the parental consent requirement is based on a rejection of the presumption of minors' incompetency and the underlying assumption that minors as a class lack decisionmaking capacity; this exception allows for individualized determinations of minors' actual decisionmaking capacity. Because it pertains to mature minors, this exception to the parental consent

requirement probably most often applies to minors in middle and late adolescence.

Exceptions for Health Emergencies

In health emergencies, medical or surgical care may be furnished to minors without parental consent. The emergency exception to the parental consent requirement was originally enunciated by the courts. More than half of the States now have statutes that codify the exception. Some of the State statutes simply authorize emergency care of a minor without parental consent; others state that a physician or other health professional who treats a minor in an emergency without parental consent is relieved from liability; and still others provide that a minor may consent to emergency care.

Exceptions for Specific Types of Health Services

Exceptions to the parental consent requirement for specific health problems or specific types of services fall into three major categories:

- exceptions for health services related to sexual activities,
- exceptions for health services related to drug and alcohol abuse, and
- exceptions for mental health services.

Exceptions for Health Services Related to Sexual Activities—Exceptions to the parental consent requirement for health services related to sexual activities are of three general types: 1) exceptions for health services related to venereal, sexually transmitted, and infectious diseases and acquired immunodeficiency syndrome (AIDS); 2) exceptions for family planning services and abortion services; and 3) exceptions for pregnancy-related health services. Services.

Exceptions for Health Services Related to Venereal, Sexually Transmitted, and Infectious Diseases and AIDS-Almost all States have enacted legislation that specifically allows minors to consent to or to receive services for a venereal or sexually transmitted disease without parental consent, More

¹²ARK. CODE ANN. § 20-9-602(7) (1987); MISS. CODE ANN. § 41-41-3(h) (Supp. 1988); N.H. REV. STAT. ANN. § 318-B:12a (1984).

¹³IDAHO CODE \$39-4302 (198 S); NEV.REV.STAT.§129.030(2) (1987). But sœ NEV.REV.STAT.§129.030(1) (1987),

¹⁴In common usage, the term "venereal disease" has been replaced by "sexually transmitted disease" (see cb. 9, "AIDS and Other Sexually Transmitted Diseases: Prevention and Services, "in Vol. II. However, because some State statutes use the older term venereal disease, it is included here.

¹⁵The effectiveness of services related t. adolescents's exual behavior—e.g., services for the prevention and treatment of AIDS and other sexually transmitted diseases, family planning services, and pregnancy-related services-is discussed in Vol. II in ch.9, 'AIDS and Other Sexually Transmitted Diseases: Prevention and Services,' and ch. 10, 'Pregnancy and Parenting: Prevention and Services.'

than two-thirds of the States have enacted legislation that specifically allows minors to obtain without parental consent health services for "venereal disease'; about one-quarter of the States have a statute that allows services without parental consent for "sexually transmitted disease. ' A few States have a statute that allows minors to obtain services without parental consent for "infectious, contagious, communicable and reportable diseases" (or some variant thereof). None of the State statutes just mentioned expressly covers testing for infection with human immunodeficiency virus (HIV), the virus that causes AIDS, but some of them may cover or could be interpreted to cover HIV testing. A few States have statutes that expressly authorize minors to consent to or to receive HIV testing without parental consent.

Most of the State statutes just mentioned allow minors of any age to consent to services or to receive services for the diseases specified without parental consent, although others specify that minors must be 12 or 14 to consent to these services. The fact that these statutes impose either no age limit or a very low age limit for minors to consent to or to receive services for these diseases without parental consent appears to stem from a legislative recognition that society has a critical interest in facilitating and encouraging access to health services to reduce the spread of disease among its citizens.

Exceptions for Family Planning Services and Abortion Services-Restrictions on access to family planning services and abortion services by adolescents are governed by Federal constitutional law as interpreted by the U.S. Supreme Court and the lower Federal courts, and the Supreme Court is the final arbiter of what is constitutionally permissible and impermissible when it comes to State-imposed restrictions-including parental consent and notification requirements-on the provision of family planning services and abortion services to minors.

In the landmark 1965 case Griswold v. Connecticut [38 1 U.S. 479 (1965)] and in Eisenstadt v. Baird [405 U.S. 438 (1972)], the U.S. Supreme Court held that an individual has a constitutionally protected "right to privacy" under the 14th amendment encompassing decisions with respect to the use of contraceptives. 17 In the 1977 case Carey v. Population Services International [431 U.S. 678 (1977)]. the U.S. Supreme Court established that minors as well as adults have a constitutionally protected right to privacy with respect to the use of contraceptives .18 A little under half of the States have statutes providing that minors may obtain without parental consent what are variously described as contraceptives, birth control services, or services for the prevention of pregnancy. Some of these statutes impose restrictions on minors obtaining these services without parental consent (e.g., that the minor be of a certain minimum age, be referred from a designated source, possess a certain maturity and intelligence, or be likely to suffer detrimental health consequences if the services are not provided). Many of them explicitly exclude or have been or could be interpreted as excluding abortion from the services that minors may obtain.

In the landmark 1973 decision *Roe v. Wade [410 U.S.* 113 (1973)], the U.S. Supreme Court held that the constitutional right to privacy encompassed a woman decision about whether to have an abortion and invalidated State criminal statutes prohibiting nontherapeutic abortions at any stage of pregnancy. At the same time, however, the Court ruled that a State did have legitimate interests (e.g., in safeguarding maternal health, in maintaining proper medical standards, and in protecting human life) that could justify State regulation of the performance of abortions .19

Since 1972, the Supreme Court has issued several decisions that have extended to minors at least some constitutional protections with respect to the right to

¹⁶Family planning services are contraceptives and other birth control services, with the exceptions of sterilization and abortion.

¹⁷In Griswold v. Connecticut [381 U.S. 479 (1965)], the U.S. Supreme Court held that State regulation of use of contraceptives by married persons invaded "the zone of privacy created by several constitutional guarantees" and struck down as unconstitutional a State statute prohibiting the use of contraceptives by married persons. In Eisenstadt v. Baird [405 U.S. 438 (1972)], the Court held that unmarried as well a.. married persons had a right to privacy with respect to contraceptive use.

the Supreme Court specifically held unconstitutional a State statute prohibiting the sale or distribution of contraceptives to minors. The Court indicated that 'State restrictions inhibiting privacy rights are valid only if they serve any significant State interest . . . that is not present in the case of an adult."

¹⁹The Supreme Court ruled in Roe v. Wade that during the first trimester of pregnancy, a State may require only that the abortion be performed by a licensed physician; that after the first trimester, a State may "regulate the abortion procedure in ways that are reasonably related to maternal health;" and that once the fetus is "viable," a State may "regulate, even proscribe, abortion except where it is necessary in appropriate medical judgment, for the preservation of life or health of the mother" [410 U.S. at 164-65].

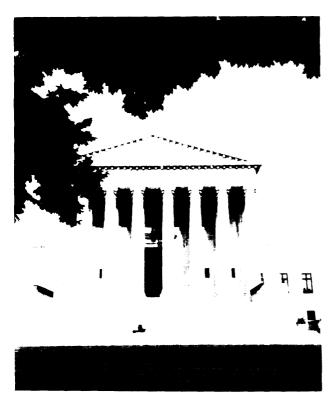


Photo credit: U.S. Congress, Office of Technology Assessment

Laws related to the allocation of authority for decisions about the provision of health services to minors have historically been the province of State legislatures, State courts, and State administrative agencies, but the U.S. Supreme Court decides whether State laws adhere to the requirements of the U.S. Constitution.

have an abortion.²⁰ The U.S. supreme Court has not held a parental consent requirement for a minor's abortion to be unconstitutional per se. It has ruled, however, that a minor's parents cannot be given an absolute veto of a minor's decision to undergo an abortion; any parental consent requirement for a minor's abortion must be coupled with the availability of a "judicial bypass" procedure, under which a minor can secure court approval for an abortion if she can demonstrate to the court that she is mature enough to make the abortion decision or that the abortion would be in her best interests. The Court has also indicated that the judicial bypass procedure must ensure a confidential and expeditious proceeding. In the wake of the Supreme Court *Roe v. Wade*

decision and related decisions, about one-quarter of the States have enacted statutes requiring parental consent to abortion for minors. Some of these State statutes have been invalidated or are currently being challenged on Federal constitutional grounds, however, so not all of the statutes are currently being enforced.

It is important to emphasize that Federal constitutional law concerning the permissible scope of State regulation of abortion as interpreted by the U.S. Supreme Court is in flux. The Supreme Court's decision in the 1989 case Webster v. Reproductive Health Services [109 S. Ct. 3040 (1989)] appears to give the States greater leeway in restricting abortions and at the same time casts doubt on the future of Roe v. Wade and other Supreme Court decisions dealing with abortion. To the extent that Webster and future rulings increase States' ability to restrict abortion generally, they may reduce minors' access to abortion--even though the decisions do not directly address the question of parental consent.

Exceptions for Pregnancy -Related Health Services— Over half of the States have statutes specifically authorizing minors to consent to pregnancy-related health services (e.g., testing to determine pregnancy, prenatal care, and delivery services). Since these consent statutes are directed at pregnant minors, they are in effect adolescent consent statutes.

Exceptions for Health Services Related to Drug and/or Alcohol Abuse²¹—All but five States (Alaska, Arkansas, Oregon, Utah, and Wyoming) and the District of Columbia have statutes specifically authorizing minors to consent to drug- and/or alcohol-related health services or to receive such services without parental consent. Two-thirds of the States have statutes covering health services related to both drug and alcohol abuse and dependency; other States have statutes covering health services related to drug abuse or alcohol abuse but not both. The majority of State statutes that allow minors to obtain treatment for drug and alcohol abuse without parental consent do not impose minimum age requirements, although some of them pertain only to minors who have reached a designated age—ranging from 12 to 16 years of age.

²⁰Notable Supreme Court decisions dealing with parental consent to a minor's abortion include *Planned Parenthood of Missouri'* v. *Danforth* [428 U.S. 52(1976)], In *Bellotti* v. *Baird* (Bellotti II) [443 U.S. 622(1979)], City of Akron v. Akron Center for Reproductive Health, Inc. [462 U.S. 416 (1973)], and *Planned Parenthood Association v. Ashcroft* [462 U.S. 476 (1983)].

²¹For a discussion of health services related to drug and alcohol abuse, seech.12, "Alcohol, Tobacco, and Drug Abuse: Prevention and Services," in Vol. II.

State statutes that create an exception to the parental consent requirement with respect to services for drug or alcohol abuse would appear to represent an acknowledgment on the part of State legislatures of the seriousness of drug and alcohol abuse problems among *adolescent minors. They would also appear to be the product of a concern on the part of State legislatures that minors may not obtain care related to such abuse if they have to secure parental consent for such care, because "communications" between parents and minors regarding alcohol or drug abuse may "be strained or nonexistent" (81).

Exceptions for Mental Health Services²²—A little under half of the States have statutes that allow some minors to obtain *outpatient* mental health services without parental consent. These statutes typically impose age restrictions and pertain only to adolescent minors. Underlying these statutes appears to be a legislative realization that a parental consent requirement might deter some adolescent minors who have mental health problems from seeking needed treatment because of a reluctance to reveal such problems to their parents.

Inpatient mental health services for minors present special problems in the area of consent. The involuntary commitment of a person to a mental institution or facility results in the deprivation of that person's liberty, so certain safeguards are in place (e.g., substantive criteria for commitment and procedures pertaining to due process) to ensure that such commitment is necessary. For voluntary commitment, however, such safeguards are not mandated, and as a concomitant of the parental consent requirement for the provision of health services to minors, parents have sometimes been allowed to make a "voluntary commitment" of a minor child to a mental institution or facility, regardless of the minor's desire or need for services.

In *Parham v. J.R.* [442 U.S. 584 (1979)], the U.S. Supreme Court rejected the contention that an adversary hearing was required to decide whether a minor may be committed by his or her parents in order to protect the minor, but held that the risk of error in the parental decision to commit a minor to a mental health facility was sufficiently great as to

call for an inquiry by a neutral fact finder to determine whether the statutory criteria for admission were met. About two-thirds of the States now have statutes that allow parents to make a voluntary commitment to a mental health facility of a minor child. These statutes vary substantially in the safeguards they provide against inappropriate use of hospitalization or institutionalization to manage "troublesome" minor children who do not have severe mental health problems.²³ According to one analysis, "In general, . . . minors are significantly less able than are adults to resist mental hospitalization sought for them by others" (85).

About half of the States have statutes that authorize minors to apply for admission as an inpatient to a mental institution or facility without parental consent. Most of these statutes impose minimum age limits, the most common being 16 years of age or older. Finally, a few States have statutes that require both the minor's consent and a parent consent for inpatient mental health services.

Confidentiality and Parental Notification Requirements

It has long been accepted that the confidentiality of the relationship between a physician and patient, as well as of the relationship between other types of health care providers and their patients or clients, is essential to a patient's trust in a health care provider and to a patient's willingness to supply information candidly (68). Courts and legislatures have established a physician-patient privilege to protect the confidentiality of communications between physicians and their patients and have established similar privileges to ensure the confidentiality of communications between other types of health care providers and their patients or clients (29). Furthermore, there is a developing case law imposing liability on physicians for unauthorized disclosure of confidential information about their patients (8) (although all health care professionals are required by law to disclose information in situations where there is a strong societal interest in disclosure-e. g., in the reporting of cases of suspected child abuse to the public child welfare authorities (47)).

²²Mental health services for adolescents are reviewed in ch.11, "Mental Health Problems: Prevention and Services," in Vol. II.

²³Some people are concerned that the rising admission to psychiatric units of private hOSpitals are indicative of widespread misuse of commitment to control "troublesome" minors (85). See ch. 11, "Mental Health Problems: Prevention and Services," in Vol. II, for further discussion.

By and large, the confidentiality of the relationship between health service providers and minors and the disclosure of confidential information by health service providers to the parents of minors or other third parties are not addressed in case or statutory law. Requirements that parents be notified of a minor's decision to obtain health services or of the minor's actual receipt of health services, however, have in fact become a' 'legal' issue. In carving out exceptions to the requirement for parental consent to the provision of health services to minors, courts and legislatures have sometimes-though not always—replaced the parental consent requirement with a parental notification requirement.

The justifications for requiring that the parents of minors be notified of the decisions of their minor children to obtain health services are essentially the same as---or at least very similar to-the justifications for requiring that parents consent to health services for minor children. One justification for parental notification requirements is to ensure that parents play an appropriate "guiding role" in counseling their minor children about health care decisions—a role assumed to be needed given the presumed incompetency of minors to make health care decisions based upon minors' assumed lack of decisionmaking capacity. Another major justification is to bolster parental direction and control of their minor children and thereby to maintain the family structure.

Parental Notification Requirements for Health Services Provided to "Emancipated," "Independent," or "Mature" Minors

The prevailing pattern in the many State statutes that authorize "emancipated minors' to obtain health services without parental consent is for these statutes to be silent concerning parental notification; only a few of these statutes contain various kinds of parental notification provisions. The same prevailing pattern is found in States' "independent minor' statutes and "mature minor' statutes.

Parental Notification Requirements for Emergency Health Services

The prevailing pattern in the many State statutes that create an exception to the parental consent



Photo credit: Los Angeles Free Clinic, Project Able

Courts and legislatures seem to regard parental notification requirements as less burdensome for adolescents than parental consent requirements, but it is not clear that adolescents in conflict with their parents make this distinction.

requirement in health emergencies is for the statutes to have no provisions concerning parental notification; only a handful of these statutes have some sort of parental notification provisions.

Parental Notification Requirements for Specific Types of Health Services

Many parental notification provisions appear in State statutes that create exceptions to parental consent requirements by allowing minors to consent to health services related to sexual activities, health services for drug and alcohol abuse, or mental health services (see discussion of these exceptions above). Although the legislatures and courts appear to regard the requirement of parental consent as more onerous from the standpoint of an adolescent than the requirement of parental notification, it is not clear that adolescents distinguish between parental consent and notification requirements. According to one observer, it is "immaterial to the adolescent just when parents learn (before or after the fact of treatment) or how parents learn (by mandatory consent, by notification, or by inadvertent disclosure through parental reading of the health record)" (43).

²⁴See, for example, *H.L.*v. *Matheson*, 450 U.S. 398 (Burger, J.) (Powell, J. concurring); *H.L.v. Matheson* 420-25 (Stevens, J. concurring); and B.D. Hofman, "The Squeal Rule: Statutory Resolution and Constitutional Implications--Burdening the Minor's Right of Privacy" (44).

²⁵See, for example, M- Boumil, "Dispensing Birth Control in Public Schools: Do Parents Have a Right To Know?" (23).

Notification Requirements for Health Services Related to Sexual Activities-Parental notification requirements related to health services involving sexual activities pertain to the three major categories of services mentioned earlier: 1) health services related to venereal, sexually transmitted, and infectious diseases and acquired immunodeficiency syndrome (AIDS); 2) family planning services and abortion services; and 3) pregnancy-related health services.

Notification Requirements for Health Services for Venereal, Sexually Transmitted, and Infectious Diseases and AI.. S-The many State statutes that authorize minors to obtain testing and treatment for venereal, sexually transmitted, or infectious diseases without parental consent generally do not require parental notification. A few States have statutes that specifically state that services for these diseases may be furnished to minors without parental notification; nearly one-third of the States have statutes that give health professionals general discretion to notify parents or discretion to notify parents under certain specified circumstances; nearly two-thirds of the States have statutes that contain no parental notification provisions; and one State has a statute that mandates parental notification under limited conditions.

The relatively small number of State statutes that permit minors to be tested and treated without parental consent for infection with HIV (the virus that causes AIDS) generally do not require parental notification. A few States have statutes with provisions giving health professionals general discretion to notify or discretion to notify parents under specified circumstances; one State has a statute that contains no parental notification provision; and one State has a statute requiring confidentiality unless a minor's HIV test results are positive, in which case parental notification is required.

Notification Requirements for Family Planning Services and Abortion Services---Only a few of the State statutes that permit minors to consent to family planning services without parental consent have provisions pertaining to parental notification of the minor's application for receipt of such services, and nearly all of these provisions allow but do not compel parental notification. As of mid-1990, the U.S. Supreme Court had not directly addressed the constitutionality of parental notification requirements that involve parents in a minor's decision about obtaining family planning services.

In 1983, the U.S. Department of Health and Human Services unsuccessfully attempted to promulgate Federal regulations requiring that family planning clinics receiving Federal funds under Title X of the Public Health Service Act²⁶ notify parents of unemancipated minor children when contraceptives were prescribed.27 These regulations-issued pursuant to a congressional amendment to the authorizing statute for the Title X family planning program that provided that "[t]o the extent practical, entities which receive grants or contracts under this subsection shall encourage family participation in projects assisted under this section" [42 U.S.C. § 300(a) (1982)]—aroused a great deal of controversy and were the subject of litigation in the Federal courts. Ultimately, two Federal courts enjoined the Department from implementing the regulations.²⁸

Although the issue of parental notification has also generated a great deal of attention in relation to minors' access to *abortions*, the U.S. Supreme Court has not dealt extensively with parental notification in cases involving abortion services for minors. In the 1981 case H.L. v. Matheson [450 U.S. 398 (1981)], however, the Supreme Court sustained the constitutionality of a State statute requiring a physician to notify "if possible" the parent of a minor upon whom an abortion is to be performed as applied to a minor living with and dependent on her parents; the Court left open the question of whether the statute would be constitutional as applied to emancipated or mature minors.

In Hodgson v. Minnesota [110 S.Ct. 2926 (1990)], handed down in June 1990, the Supreme Court

²⁶For further discussion of the Title X family pl arming program, see ch. 10, "Pregnancy and Parenting: Prevention and Services," in Vol. II and ch. 19, "The Role of Federal Agencies in Adolescent Health," in this volume.

²⁷The regulation provided that 10 days after prescribing a contraceptive drug or device for a minor, the family planning clinic must notify the minor's parent [45 CFR § 59.5(a) (12)(i)(A)].

²⁸ The Court of Appeals for the Second Circuit held that the 1981 amendment to Title X did not authorize the regulation mandating parental notification [New York v. Heckler, 719 F.2d 1191 (2d Cir. 1983)]. The Court found that Congress did not intend to require parental notification but merely to encourage parental involvement. The Court of Appeals for the District of Columbia held that the regulation requiring parental notification was inconsistent with congressional intent with respect to Title X [Planned Parenthood Federation of America v. Heckler, 712 F.2d 650 (D.C. Cir. 1983)].

struck down as unconstitutional a section of a Minnesota statute requiring that both parents of an unemancipated minor be notified before she undergoes an abortion, except under very limited circumstances. However, the Court upheld the constitutionality of a section of the statute providing for the same two-parent notification requirement with the addition of a "judicial bypass" procedure. In a contemporaneous decision, Ohio v. Akron Center for Reproductive Health [110 S. Ct. 2972 (1990)], the Court upheld the constitutionality of an Ohio statute making it a crime for a physician or other person to perform an abortion on an unmarried, unemancipated minor unless: 1) there was timely notice to one of the minor's parents, her guardian, or custodian; 2) the minor's parents, guardian, or custodian had consented to the abortion; 3) a juvenile court had issued an order authorizing the minor to consent to the abortion, thereby bypassing parental notification for consent; or 4) judicial inaction under certain circumstances constitutes constructive authorization for the minor to consent.

A little under one-quarter of the States have statutes requiring parental notification of a minor's abortion decision. In the wake of the *Webster ruling*, there has been increased debate as to whether parental notification of abortions involving minors should be required, ²⁹ and the Supreme Court's decisions as to the constitutionality of the two State statutes just mentioned may furnish an impetus for additional State legislative activity aimed at requiring parental notification in the case of a minor's decision to have an abortion.

Notification Requirements for Pregnancy-Related Health Services-The many State statutes that authorize minors to obtain pregnancy-related health services without parental consent generally do not require parental notification. One State has a statute that explicitly provides that prenatal care may be furnished without parental notification; somewhat under one-third of the States have statutes that have no provisions regarding parental notification; and about one-fourth of the States have statutes that provide for parental notification at the discretion of health professionals.

Notification Requirements for Health Services Related to Drug and/or Alcohol Abuse-The

many State statutes that allow minors to obtain health services for drug and/or alcohol abuse without parental consent exhibit considerable variation when it comes to parental notification provisions-and this variation makes generalizations difficult. Some of these State statutes are silent as to parental notification; some of the statutes require that a minor's drug or alcohol abuse treatment be kept confidential under specified circumstances; some of the statutes leave parental notification up to the discretion of the health professional or to the discretion of the health professional under certain specified circumstances; a few State statutes require parental notification attempts; and a few of the statutes require parental notification or require parental notification under certain specified circum-

In 1987, the U.S. Department of Health and Human Services issued a final rule for federally funded alcohol and drug abuse programs that prohibits such programs from notifying a minor's parent of the minor's application for treatment without the minor's written consent to notification in States where State law permits minors to obtain alcohol or drug abuse treatment without parental consent [42 CFR, Part 2 § 2.14 (1989)]. This prohibition covers, among other things, the disclosure to a minor's parent of patient identifying information for the purpose of obtaining financial reimbursement; however, "these regulations do not prohibit a program from refusing to provide alcohol or drug abuse treatment until a minor consents to the disclosure necessary to obtain reimbursement. . . " [42 CFR, Part 2\$2.14 (1989)]. In States where State law requires parental consent to alcohol or drug abuse treatment, the rule states that the fact of a minor's application for treatment may be communicated to the minor's parent only if: a) the minor has given written consent; or b) the minor "lacks the capacity for rational choice' regarding such consent (e.g., because of extreme youth or physical condition) and the minor's "situation poses a substantial threat to the physical well-being of the minor or other person' that may be alleviated by parental notification [42 CFR, Part 2 § 2.14 (1989)].

Notification Requirements for Mental Health Services-The many State statutes under which minors can consent to mental health services or

^{2°} See C. Collins, "Abortion Focus Shifting to Teenagers" (30); New York Times, "Kansas Is Urged To Curb Abortion" (70); New York Times, "Virginia Senators Stall Bill To Curb Abortion" (71).



Photo credit: Joe M. Sanders, American Academy of Pediatrics

Laws requiring parental consent and notification in the provision of health services to adolescents do not affect adolescents' access to services unless there are conflicts or potential conflicts between adolescents, their parents, and health care professionals.

receive mental health services without parental consent vary in terms of parental notification requirements. The majority of State statutes that allow minors to consent to outpatient mental health services are silent as to parental notification, and the remainder of statutes specify that mental health treatment should be confidential, specify that notification is at the discretion of health professionals, or mandate parental notification under designated limited conditions. The majority of State statutes that allow minors to consent to inpatient mental health services similarly do not have parental notification provisions, and the remainder provide for parental notification at the discretion of health professionals, or provide for notification under certain circumstances. Perhaps not surprisingly, inpatient mental health statutes are more likely than outpatient statutes to require or permit parental notification.

The Impact of Law Requiring Parental Consent and Notification on Minors' Access to Health Services

What is the impact of law requiring parental consent to health services for minors or requiring parental notification of the provision (or intended provision) of health services to minors? More specifically, what is the impact of parental consent and notification requirements on minors' access to health services and on minors' utilization of health services?

Several factors affect the impact of legally mandated parental consent and notification requirements on minors' access to and utilization of health services. One factor is whether--and if so, to what degree--there are actual or potential conflicts between minors, the parents of minors, and health professionals in the making of health care decisions involving the minor. As noted earlier, laws requiring parental consent and notification do not become critical, or even relevant, unless there are such conflicts. In some cases, the way a health professional presents information to a minor and the minor's parents and what kind of relationship he or she has with them may have a decisive influence on the nature and extent of such conflict. If a health professional has knowledge, skills, and experience regarding the management of potential conflicts, some conflicts may well be avoided (43,77).

On the other hand, some conflicts between minors, their parents, and health professionals over health care decisions affecting the minor are probably unavoidable. There is some evidence that actual or potential conflicts do occur in a significant number of cases involving decisions about the provision of family planning and abortion services to adolescent minors .30 What is not known, however, is whether-and if so, to what degree--actual or potential conflicts occur in cases involving decisions about *other* health services that minors, particularly adolescent minors, may want or need.

Another factor that affects the impact of legally mandated parental consent or notification requirements for the delivery of health services to minors is whether--and if so, to what degree--wealth care providers comply with these requirements in providing health services to minors. Laws might be expected to evoke compliance, carrying with them as they do sanctions for violations and constituting as they do a societal declaration that certain conduct is right or wrong. Clearly, however, laws differ in their effectiveness. Noncompliance with parental consent or notification laws on the part of health professionals might occur because the professionals misunderstand or do not know the legal requirements. Noncompliance might also occur because the legal requirements, at least as applied to particular factual situations, are at odds with the ethical

³⁰See, for example, Brief for Petitioners at 16-23 Hodgson v, Minnesota [853 F.2d 1452 (8th Cir. 1988) (en Me), appeal filed (U.S. Feb. 3, 1989) (No. 88-11257), 110 S.Ct. 400 (1989)1.

standards as expressed in statements by professional organizations of their profession (see box 17-A) or with their personal ethical values and norms. OTA is unaware of any empirical studies and data concerning compliance and noncompliance with legally mandated parental consent or notification requirements that would permit valid conclusions about the extent of compliance and noncompliance among health service providers.

To the extent that legally mandated parental consent and notification requirements are adhered to by health professionals, the issue arises of whether and if so, to what degree-such requirements may operate as barriers to adolescents' access to needed health services. As noted earlier, it is not clear that adolescents distinguish between parental consent and notification requirements. With parental consent and notification requirements in place, one possible scenario is that a substantial number of parents of adolescents would frequently and strongly object to the provision to their children of at least some health services-for example, family planning or other services associated with sexual activity, services for substance abuse, and services for mental health problems. A possibly related scenario is that a large number of adolescent minors would be unwilling to reveal to their parents their need for health servicesor at least their need for certain services associated with sexual activity, drug or alcohol abuse, or mental health problems—and therefore would delay or be deterred from seeking these services entirely.

Several empirical studies concerning the impact of parental consent and notification requirements indicate that such requirements-at least in the case offamily planning and abortion services--do create barriers to adolescents' access to and utilization of services (21,22,25,26,28,78,79,87,88). What cannot be said with certainty, however, is whether the findings of these studies of the impact of parental consent and notification requirements on adolescents' access to family planning and abortion services can be extrapolated to other types of health services.

One other point related to evaluating the impact of parental consent and notification requirements is deserving of mention. Even if the laws in a given jurisdiction do not *require* that a parent consent to health services for a minor and/or that the parent be notified of the provision or intended provision of



Photo credit: March of Dimes Birth Defects Foundation

In the case of family planning and abortion services, studies have found that parental consent and notification requirements pose a significant barrier to adolescents' access to and utilization of services. Quite probably, such requirements also pose similar barriers to adolescents' access to other types of services (e.g., mental health treatment, drug abuse treatment, alcohol abuse treatment).

health services to a minor, health care providers—both institutional providers (e.g., hospitals, clinics, and health maintenance organizations) and individual providers—may as a matter of policy or practice refuse to provide services to minors without parental consent and/or notification. One of the main reasons that health care providers may refuse to provide services without parental consent is probably financial—i.e., providers may be concerned that a minor will be unable to pay for services provided and that the minor's parents will not pay for services because they have not consented to or been notified of the

Box 17-A--Professional Ethical Standards Relevant to Consent and Confidentiality

A central principle of medical ethics is that "a physician may not reveal the confidences entrusted to him in the course of medical attendance. . . unless he is required to do so by law or unless it becomes necessary in order to protect the welfare of the individual or the community" (9). Many organizations of physicians, nurses, psychologists, social workers, and other professionals engaged in providing health services to adolescents have issued or approved professional ethical standards that similarly stress the importance of maintaining confidentiality between the health professional and the patient or client being served but at the same time acknowledge that legal obligations and the welfare of the individual and the community may take precedence over confidentiality (2-4,6,7,9-16,65-67).

Few of the ethical standards issued or approved by organizations of health professionals speak directly to issues of consent and confidentiality as they arise in the provision of health care to *adolescents*. A conference sponsored by the American Academy of Pediatrics in 1981 sought to address that problem. Conference participants from a variety of disciplines agreed that the following principles should govern consent and confidentiality m adolescent health care:

- With respect to adolescence, there exists an enduring need to balance delicately the relative rights and needs
 of minors to confidential health services with the relative rights and responsibilities of parents toward their
 offspring.
- Adolescents should have access to needed health services.
- Adolescents, unless fairly adjudged incompetent, should participate in decisions pertaining to their health.
- The concept of "mature minor" and the capacity of that individual to consent is recognized.
- Even when adolescents seek health care on their own consent, they should be encouraged to involve their parents, unless there is compelling reason not to do so. (In that case, often an alternative adult adviser/relative is appropriate.)
- Chronologic age is not a suitable yardstick to determine an adolescent's maturity and capacity to give informed consent. Development criteria are far more telling, as applied on an individual basis.
- Adolescents generally should be entitled to confidentiality in their own health care, and that presumption should be overridden only by good reason.
- Parental notification should be encouraged but not be made mandatory in the provision of adolescent health care, especially inasmuch as the absence of guaranteed confidentiality could deter many young persons from seeking and receiving necessary services.
- Adolescents should have the same right of access to their health care records as do adults unless there is compelling reason to the contrary.
- Disclosure of health data to third parties, such as health insurers, should only be with parents' informed consent and/or that of adolescents if it pertains to care they have received on their own. As a general rule, adolescents should retain the right to consent to such disclosure with or without parental participation, and even if the adolescent did not originally consent to the health care, unless there is a compelling reason not to.
- Health providers and third-party repositories periodically should review data collected during an individual's minority to reassess its relevance, expunging data no longer needed.
- To protect adolescents, they should be provided with some record as to where their health information was sent, when it was sent, and for what purpose (5).

In 1989, the American College of Obstetricians and Gynecologists (ACOG) issued a policy statement setting forth the most extensive ethical standards pertaining to consent and confidentiality in adolescent health care to date. The statement, which has since been approved by the American Academy of Family Physicians, the American Academy of Pediatrics, the NAACOG (the Organization for Obstetric, Gynecologic, and Neonatal Nurses), and the National Medical Association, provides as follows:

- 1. Health professionals have an ethical obligation to provide the best possible care and counseling to respond to the needs of their adolescent patients.
- 2. This obligation includes every reasonable effort to encourage the adolescent to involve parents, whose support Can, in many circumstances, increase the potential for dealing with the adolescent's problems on a continuing basis.
- 3. Parents are frequently in a patient relationship with the same providers as their children or have been exercising decisionmaking responsibility for their children with these providers. At the time providers

establish an independent relationship with adolescents as patients, the providers should make this new relationship clear to parents and adolescents with regard to the following elements:

- a. The adolescent will have an opportunity for examination and counseling apart from parents, and the same confidentiality will be preserved between the adolescent patient and the provider as between the parent/adult and the provider.
- b. The adolescent must understand under what circumstances (e.g., life-threatening emergency) the provider will abrogate this confidentiality.
- c. Parents should be encouraged to work out means to facilitate communication regarding appointments, payment, or other matters consistent with the understanding reached about confidentiality and parental support in this transitional period when the adolescent is moving toward self-responsibility for health cam.
- 4. Providers, parents, and adolescents need to be aware of the nature and effect of laws and regulations in their jurisdictions that introduce further constraints on these relationships. Some of these laws and regulations are unduly restrictive and in need of revision as a matter of public policy. Ultimately, the health risks to the adolescents are so impelling that legal barriers and deference to parental involvement should not stand in the way of needed health care (7).

The ACOG policy statement and American Academy of Pediatrics conference principles encourage parental involvement in adolescent health care decisions but do not endorse the current legal requirements of parental consent and notification. The support of health professionals serving adolescents for that statement and principles indicates that many of these professionals are-at least in theory-more willing than most courts or legislatures have been to grant adolescents autonomy in health care decisionmaking and to afford protection to the confidentiality of the relationship between a provider of health services and an adolescent patient or client. Furthermore, at least one empirical study suggests that health professionals are willing to support these ideas in practice (60).

A question that remains is how helpful existing standards in the form of statements by professional organizations are in resolving the kinds of ethical problems that professionals encounter in providing health services to adolescents. The following situations, compiled by a national authority on adolescent medicine, are illustrative of potential conflicts between interests of the adolescent, the adolescent's parents, and the state (77):

- A 16-year-old boy is discovered to have a malignant bone tumor. Appropriate treatment requires amputation of his leg. His parents consent to the surgery but he refuses. He will accept all other forms of treatment but would 'rather die with both legs than survive as a cripple! Do you operate without the consent of the boy? Do you seek a court order against the wishes of the boy?
- A 17-year-old boy is admitted to the intensive care unit with multiple fractures and disorientation. He was the driver of an automobile involved in a collision in which three passengers were killed. As part of the evaluation of his state of consciousness you determine that his blood alcohol level is well above the legal limits for intoxication. Do you share this information with his family in explanation for his confusion? Do you share this information with the authorities who are investigating this fatal accident?
- A 16-year-old girl is brought to care by her mother who is concerned about her daughter's poor school performance and disruptive behavior. In your private interview with the girl, she confides that she is smoking marijuana a few nights each week The girl feels that her current problems relate to the unrealistic expectations of her mother regarding performance and behavior. She insists that the confidentiality of her interview be respected and that the information about her drug use not be shared with her mother. Do you tell the mother anyway? What if the mother specifically asks, "Is my daughter using drugs?" The mother requests that a portion of the urine sample collected for routine analysis be sent for drug testing. Do you accede to this request?
- A 15-year-old girl returns with her parents to discuss her recently diagnosed pregnancy. Her parents are certain that the only acceptable course of action is to terminate the pregnancy. The girl is adamant in her refusal to consider an abortion. What do you do?
- A 16-year-old girl is brought for evaluation by her mother because of a complaint of abdominal pain. Physical examination and laboratory evaluation reveal a vaginal discharge secondary to gonorrhea. The girl admits to multiple brief intimate relationships over the past few months. She states that her mother would "kill her" if she found out. You know the family and the mother is a bit of a tyrant with a quick temper. What do you tell the mother?

Continued on next page

Box 17-A-Professional Ethical Standards Relevant to Consent and Confidentiality-Continued

- An 18-year-old homosexual male comes in and requests testing for AIDS. His affect is depressed and upon questioning he admits to frequent suicidal ideation and one prior attempt. He is certain "he would kill himself" if he finds out he has AIDS, but must know the results of his testing because not knowing is "driving him crazy." Do you do HIV testing?
 - You are caring for a 17-year-old intravenous drug abuser whom you know to be HIV positive. For the very first time he appears to be sincerely motivated to enter into a drug abuse treatment program. He asks that you complete the required preadmission history and examination form but insists that you make no mention of his HIV status. Do you fill out and sign the form omitting reference to his HIV status?
 - A recently married 18-year-old with a past history of homosexual activity is found to be HIV positive. He refuses to inform his bride. He is certain she would leave him. Do you tell her?
 - You are caring for a 17-year-old who has AIDS secondary to a transfusion. His 16-year-old girl friend is aware of the diagnosis, but they continue to have unprotected intercourse. She "doesn't care"; she "loves him." Do you inform her parents?

Unfortunately, existing ethical standards by professional organizations would appear to give little concrete guidance and direction to adolescent health service providers in resolving many of these problems. Perhaps the limitation of professional standards in giving guidance in actual situations is inevitable given the sui generis nature of most ethical problems. It is very troublesome, however, given the complex dilemmas that the service providers often encounter in serving adolescents.

provision of services. Another reason may be providers' concern that the effectiveness of the services provided will be reduced by lack of parental involvement or belief that the effectiveness of the services provided will be enhanced by parental involvement.

Minors' Competency To Make Health Care Decisions

As noted at the beginning of this chapter, individuals traditionally have been treated as legally competent or incompetent for purposes of health care decisionmaking on the basis of their age rather than a determination of their actual capacity for decisionmaking. As a general rule, the law presumes that adults are competent to consent to health care and that minors are incompetent. The legal presumption that minors as a class are incompetent to consent to health services rests at least in part on the assumption that minors as a class lack the requisite decisionmaking capacity. The legal presumption that adults are competent is rebuttable under some circumstances upon a factual showing of actual lack

of decisionmaking capacity; however, the legal presumption that minors are incompetent is not rebuttable by a factual showing of actual presence of decisionmaking capacity in the absence of legislatively or judicially sanctioned rules permitting such a showing.

The factual validity of assumptions that minors lack the requisite capacity to make health care decisions has been increasingly challenged.³² Accordingly, the presumption that minors are incompetent to make health care decisions has been increasingly subject to criticism on the ground that it inequitably denies minors in middle or late adolescence-some of whom actually have the requisite decisionmaking capacity-the power to make their own determinations about obtaining health services (82). Since assumptions concerning minors' lack of health care decisionmaking capacity seem largely to reflect the intuition of judges and legislators rather than hard evidence, it is important to identify empirical research bearing upon the validity of these assumptions and to evaluate whether such research supports modification or elimination of the pre-

³¹If a parent has consented to health services for his or her minor child, the parent is usually financially liable for the services. If a parent has not consented to health services for the minor child, however, the parentis usually not financially liable unless the services are determined to be "necessary.' If the parentis not financially liable, the health care provider may attempt to collect from the minor child, but collection may prove difficult because the minor may have the power to disaffirm the contract for services or may have insufficient financial resources to pay for the services. As noted at the beginning of this chapter, one of the rationales for the parental consent requirement seems to be to assure providers of the availability of a payment source for their services.

³²See, for example, G. Melton, "Children's Consent: A Problem in Law and Social Science" (61).

sumption that minors are incompetent to make their own health care decisions.

Empirical research bearing on the competency of minors to make health care decisions was reviewed by OTA's contractors and is discussed below. Before turning to that research, however, it is necessary to examine two definitional issues: frost, what constitutes *effective legal consent* to health services; and second, what constitutes *legal competency* to make such consent.

Ambiguities in Legal Definitions of Consent and Competency

What Constitutes Effective Legal Consent to Health Services

As alluded to at the beginning of this chapter, the tort law doctrine of informed consent requires physicians and surgeons to obtain from their patients informed consent for medical treatment or surgery; failure to obtain informed consent may give rise to civil liability .33

The informed consent doctrine has been developed in judicial opinions and codified by legislation and does not readily lend itself to a concise summary. Nevertheless, one leading tort law authority has summarized the doctrine as follows:

The informed consent doctrine is based on principles of individual autonomy, and specifically on the premise that every person has the right to determine what shall be done to his own body. Surgeons and other doctors are thus required to provide their patients with sufficient information to permit the patient himself to make an informed and intelligent decision on whether to submit to a proposed course of treatment or surgical procedure. Such a disclosure should include the nature of the pertinent ailment or condition, the risks of the proposed treatment or procedure, and the risks of any alternative methods of treatment, including the risks of failing to undergo any treatment at all. Thus, although the procedure is skillfully performed, the doctor may nevertheless be liable for an adverse consequence about which the patient was not adequately informed.

In addressing the perplexing question of whether the patient needed to know about a particular

undisclosed risk in order to make an informed decision, the courts often speak in terms of the materiality of the risk: the doctor's duty is to disclose all risks which are "material. The extent of this duty to disclose has traditionally been based upon a professional medical standard-whether physicians customarily inform their patients about the type of risk involved, or whether a reasonable physician would make the disclosure in the circumstance, Since the use of a professional standard paternalistically leaves the right of choice to the medical community, in derogation of the patient's right of self-determination, a number of recent cases have defined the duty in terms of the patient's need to know the information-based on whether a reasonable person in the patient's position would attach significance to the information.

In addition to proving the doctor's failure to provide sufficient information, on whatever standard, the plaintiff must also establish a causal link between the nondisclosure and his harm, by proving that he would not have undergone the treatment had he known of the risk of harm that in fact occurred. ... [Citations omitted] (53).³⁴

Rationales for the informed consent doctrine are to promote the patient's autonomy and protect the patient's right of self-determination (64), to protect patients against depersonalized authoritarian medical treatments, and to encourage rational decision-making (59). It is important to note that focus of the doctrine as it has been articulated and applied is on the *duty of health professionals to disclose information* to an individual. The focus has not been on the individual's actual understanding of the information disclosed.

What Constitutes Legal Competency To Make Health Care Decisions

The legal concept of competency has a very long history and is central to existing laws governing health care decisionmaking with respect to adolescents. On the one hand, as noted earlier, the well-established legal requirement that parents must *consent* to the provision of health services for their minor children is partially an outgrowth of the presumption that minors are incompetent (which in turn is based on assumptions of their lack of decisionmaking capacity). To some extent, judicial

³³T0 be legally effective, consent to health care services must be both "informed" and also be "voluntary." The concept of voluntariness is not well defined (17)

³⁴ F_a discussion of the development of the informed consent doctrine, see P.S. Appelbaum, C.W. Lidz, and A. Meisel, Informed Consent: Legal Theory and Clinical Practice (17); for a State-by-State analysis of the application of the informed consent doctrine, see A.J.Rosoff, Informed Consent: A Guide for Health Care Providers (73).

and statutory parental *notification* requirements applied to minors are also derived from this presumption and assumption. On the other hand, "mature minor" and some other exceptions to the parental consent requirement, as discussed earlier in this chapter, represent a rejection of the presumption of minors' incompetence (and underlying assumptions of their lack of decisionmaking capacity) as applied to some minors under certain circumstances.

Unfortunately, neither the courts nor the legislatures in this country have furnished much guidance as to the content and meaning of competency in the context of health care decisionmaking. The U.S. Supreme Court has most fully articulated its assumptions concerning the minors' lack of health care decisionmaking capacity (which underlie the presumption of minors' incompetency to make health care decisions) in decisions dealing with minors' rights to obtain contraceptives and abortions without parental involvement and in decisions dealing with the civil commitment of minors by parents (see discussion above). A thread that runs through these Supreme Court decisions is the Court's concern that minor children do not possess the intelligence, maturity, and experience that their parents possess. Another thread that runs through these decisions is the Court's concern that minors are not capable of making informed and voluntary decisions. The Court's specific concerns in this regard are that minors may not understand or appreciate the short-or long-term consequences of their decisions, that they may be susceptible to interpersonal pressures in making decisions, and that they may make unwise decisions detrimental to their welfare.

Courts-and, to a lesser extent, legislatures—have probably come closest to enunciating a *standard* for determining the competency of minors to make health care decisions in connection with exceptions to parental consent requirements for "mature' minors (see discussion above). The standard for judging competency in these cases is essentially whether the minor is capable of understanding the nature and consequences of proposed medical or surgical treatment and procedures. Unfortunately, however, this standard for determining a minor's competency provides little real assistance for its application in particular cases.³⁵

Recognizing the need to define with more specificity a criterion for determining whether a person, including an older minor, is competent to make health care decisions, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research noted that three general criteria have been used to determine if a patient lacks capacity to make health care decisions: the outcome of the decision, the status or category of the patient, and the patient's fictional ability as a decisionmaker.

The outcome approach-which the Commission expressly rejects-bases a determination of incapacity primarily on the content of a patient's decision. Under this standard, a patient who makes a health care decision that reflects values not widely held or that rejects conventional wisdom about proper health care is found to be incapacitated.

Using the status approach, certain categories of patients have traditionally been deemed incapable of making treatment decisions without regard to their actual capabilities. Some of these categories of patients—such as the unconscious--correspond closely with actual incapacity. But other patients who are presumed to be incapacitated on the basis of their status may actually be capable of making particular health care decisions. Many older children, for example, can make at least some health care decisions, mildly or moderately retarded individuals hold understandable preferences about health care, and the same may be true in varying degrees among psychotic persons.

The third approach to the determination of incapacity focuses on an individual's actual functioning in decisionmaking situations rather than on the individual's status. This approach is particularly germane for children above a certain age variously described as from seven to mid-teens.

The Commission recommends that determinations of incapacity be guided largely by the functional approach, that individuals not in certain basic categories (such as under the age of 14, grossly retarded, or comatose) should be assumed to possess decisionmaking capacity until they demonstrate otherwise, and that incapacity should be found to exist only when people lack the ability to make decisions that promote their well-being in conform-

ity with their own previously expressed values and preferences. [Citations omitted] (72).³⁶

The failure of courts and legislatures to furnish much guidance as to the content and meaning of competency in terms of health care decisionmaking has had important implications for the strategies adopted in empirical studies of the capacity of minors to make health care decisions. Because courts have not provided operational definitions of legal standards for minimally competent decisionmaking, researchers have been unable to use an operational definition of competency corresponding to the legal definition. Thus, researchers seeking to test the validity of the law's presumption that adults are competent and minors are incompetent to make health care decisions have had to resort to an alternative strategy-namely, comparing decisionmaking by minors to decisionmaking by adults (i.e., individuals age 18 and over). Since adults are presumed by the law to be competent, adults' decisionmaking capabilities implicitly set the standard against which the decisionmaking capabilities of minors are to be judged. If the decisionmaking of minors and adults were found to be indistinguishable, the argument for lowering the age of legally effective consent would be strengthened, although other considerations would have to be taken into account as well. Virtually all of the empirical research on the competency of minors to make health care decisions reviewed by OTA's contractors recognizes that the standard of comparison is the decisionmaking ability of adults.

Empirical Research on Minors' Competency To Make Health Care Decisions

To review the empirical research on the competency of minors to make health care decisions, OTA's contractors selected a core group of seven empirical studies that address the cognitive development of minors and tested whether minors differ from adults in their ability to make health care decisions (1,1 8,48,49,55,56,86). Those core studies, which are listed in table 17-1, share the following characteristics:

- they involve health care decisionmaking;
- they involve participants whose ages span or overlap the range of 10 to 18 years;
- they involve comparison groups with at least some subjects legally considered adults-i. e., age 18 or over³⁷ (although no adult participants in the core studies were older than 25 and most were 21 or younger); and
- they appear to be methodologically adequate.

In addition to the core group of studies, a few other studies that lack one or more of the features just mentioned but nevertheless provide insight into decisionmaking by minors were reviewed (40,51,57, 58,76). Some of these other studies address decisionmaking domains not addressed in the core group of studies (e.g., legal decisionmaking); and some of them deal with the effect on decisionmaking of a variable or variables other than age (e.g., the differential vulnerability of minors and adults to social influence of peers, family, or professionals).

Findings of the Core Group of Empirical Studies on the Age-Competence Relationship in Health Care Decisionmaking

The findings of the core group of seven empirical studies on the age-competence relationship in health care decisionmaking reviewed by OTA contractors are summarized in table 17-1 and discussed in more detail below. These core studies generally found few differences in health care decisionmaking as a function of age for adolescents as young as 14 or 15 years of age. It is important to note that most of the core studies did not collect information on decisionmaking by adults older than 25, and most of the core studies did not collect information on decisionmaking by adolescents under age 13 (i.e., ages 10 to 12).

Lewis, 1980--The 1980 study by Lewis compared hypothetical pregnancy decisions for 42 unmarried minors (ages 13 to 17) and young adults (ages 18 to 25) awaiting the results of pregnancy tests in a clinic (55). Those who learned they were pregnant would be faced with the decision whether to have an abortion or deliver a child. All 42

³⁶See also L.H.Roth, A. Meisel, and C.W. Lidz, 'Tests of Competence To Consent to Treatment' (74), (The various legal, medical and psychiatric tests of competency being utilized may be categorized as: evidencing a choice, ''reasonable' outcome of choice, choice based on ''rational' reasons, the ability to understand, and actual understanding.)

³⁷As noted previously, this OTA Report focuses on individuals ages 10 through 18. Legally, 18-year-olds are considered adults in all but three States (where the age of majority is 19). In the studies comparing decisionmaking capabilities of adults and minors listed in table 17-1, therefore, 18-year-olds are regarded as adults.

Table 17-1—Summary of Seven Core Empirical Studies of the Age-Competency Relationship in Health Care Decisionmaking

			Influence of age on decisionmaking	
study ^a	Sample	Decision domain	No differences	Differences found
Lewis, 1980	N=42 Ages 13-17 V. 18-25 Possibly pregnant, un- married females; diverse socioecnomic statuses; urban California	Pregnancy: knowledge of law, source of advice, reasons for choice	In knowledge of laws; in number of types of peo- ple consulted; in advice expected; in considera- tion of childrearing abil- ity; in hypothetical ad- vice giving.	The 18- to 25-year olds were more likely to COnsult a professional; consider their own ability to care for a child. The 13- to 17-year olds were more likely to consider impact of a child on their
				parents; to consider possi- bility of deformity; and to perceive decision as ex- ternally determined.
Lewis, 1981	N = 108 Ages 12-19 (grades 7-8,10 and 12) Middle to upper socioeconomic status; 87% expected to attend college; San Francisco	Cosmetic surgery, choice of custodial parent, research: on acne medication, on "mind"	In consulting with peers or parents; in revising attitudes in light of new information.	With increasing age, there was increasing probability of mentioning risks, future consequences, and desirability of consulting an independent specialist, as well as caution against persons with vested interests,
Weithorn and Campbell, 1982	N=96 Ages 9, 14, 18, 21 Half male, half female; white; middle socioeco- nomic status; younger groups, Long Island; older groups, Washington, DC	choice of treatment alter- natives for diabetes, epi- lepsy, enuresis, depres- sion; risks, benefits, etc.	In expression of a decision preference or choice of treatments among 14-,18-, 21-year-olds; in reasons for choice (except as noted); in factual understanding and appreciation of problems/consequences (except as noted).	The 9-year-olds differed from other groups on treatment choices for depression; they were more likely to choose inpatient treatment. In reasons for choices, 9-year-olds differed from other groups; 14-year-olds differed on epilepsy. In factual understanding of the condition and appreciation of the consequences, 9-year-olds differed from all others.
Belter and Grisso, 1984	N=60 Ages 9, 15, 21 Ail males; predominantly white; middle-class; av- erage to above average IQ	Recognizing and protect- ing against violations of patients' rights by a pro- fessional	In recognition or protection of patients' rights between 15-and 21 -yearolds who were briefed about such rights.	The 9-year-olds showed less recognition of patients' rights violations and failed to protect their own rights more often than the other two groups.
Kaser-Boyd et al., 1985	N =62 Ages 10-13 v. 14-20 Behaviorally disordered, emotionally disturbed, learning disabled; some with, without prior ther- apy experience; 70% mid- dle socioeconomic status, 20% low-mid, 10% low; mostly white, 16 nonwhite; 670/. male;	Psychological treatment; risks, benefits	In identifying risks [Author's note: ns were too small in some instances to complete chi-sq]; in 8 benefit dimensions.	Nonsignificant trend for 10- to 13-year-olds to say did not know if risks existed. In benefits, 14- to 20-year-olds thought psychotherapy helped you learn new things. The 14- to 20-year-olds used more abstract concepts in describing benefits.

probably LA.

Health Care Decisionmaking—Continued							
			influence of age on decisionmaking				
	Sample	Decision domain	No differences	Differences found			
oyd et al., 1986	N = 75 Ages 10-19 Adolescents with mild to	Psyological treatment; risks, benefits, and irrel- evant considerations	In distinguishing risks, benefits, and irrelevant considerations; in treat-	None			

Table 17-1—Summary of Seven Core Empirical Studies of the Age-Competency Relationship in

study' Kaser-Bo severe learning and ment decision vignettes. behavioral problems; mostly upper middle socioeconomic status, low to mid socioeconomic status; mostly white, 14 nonwhite; probably I-A. Ambuel, 1989 N = 75Broad range of knowl-In cognitive or volitional Females ages 13 to 15 Ages 13-21 edge, affect, decision competence (except who did not consider abor-All females; diverse raconflict around among females ages 13 tion scored lower on the cial, economic, and reunplanned pregnancy to 15 who did not conmeasure of volitional com ligious backgrounds sider abortion an alterpetence and most measures of cognitive competence.

SOURCE: Office of Technology Assessment, 1991, adapted from J. Gittler, M. Quigley-Rick, and M.J. Saks, "Adolescent Health Care Decisionmaking: The Law and Public Policy," prepared under contract to the Carnegie Council on Adolescent Development for the Office of Technology Assessment, U.S. Congress, Washington, DC, February 1990.

participants were asked to respond to a hypothetical question seeking advice for a person in that situation.

In terms of the decision as to whether to have a child, this study found that the minors and young adults did not differ from each other in terms of knowledge of relevant laws, number or types of people consulted, the advice anticipated from those consulted, or considerations of childrearing ability in giving advice to another person.

On the other hand, the young adults in the study were more likely than the minors to want to consult an independent professional and more likely to consider their own childrearing abilities in deciding whether or not to have a child themselves. The minors were more likely to consider the impact of their child on their own parents and gave more weight to the likelihood of possible deformity of their baby. Furthermore, the minors tended to perceive the decision as being more externally determined than as being within their own power to make. (This perception may simply reflect the minors' life experience in other domains.)

Lewis, 1981—The 1981 study by Lewis asked students ages 12 to 19 (grades 7-8, 10, and 12) what advice they would give peers who were faced with a variety of choices: cosmetic surgery, choice of custodial parent, a research trial involving acne medication, and research on "the mind" (56). This

study found no age-related differences in advice the participants said they would give regarding consultation with peers or parents and found no age-related differences in participants' revisions of attitudes in the light of new information.

On the other hand, this study found that with increasing age from 12 to 19, there was an increasing tendency among participants to mention risks, future consequences, and the desirability of consulting an independent specialist (i.e., a specialist without vested interests in the choice made), and there was an increasing tendency to express caution about the advice of persons with vested interests in the choice made.

Weithorn and Campbell, 1982—The 1982 study by Weithom and Campbell presented hypothetical treatment dilemmas involving four health problems (diabetes, epilepsy, enuresis, and depression) to participants ages 9, 14, 18, and 21 and asked participants what decisions they would make and the reasons for those decisions (86).

This study found that groups of participants ages 14, 18, and 21 did not differ in their decisions or reasons for decisions. Moreover, the decisions of these participants did not differ from those recommended by health professionals for the problems in question. Groups of participants ages 14, 18, and 21 also did not differ from each other on tests of factual

aFull citations are listed at the end of this chapter.

understanding of the health problems or appreciation of the consequences associated with various options.

The group of 9-year-olds, this study found, did differ in many ways from the older groups. The 9-year-olds were more likely than the older groups to select inpatient treatment for depression. Indeed, the study found an overall trend for younger participants to be accepting of inpatient treatment and older participants to reject it. The 9-year-olds also differed from the older groups in the reasons for their choices of treatment, in factual understanding of the conditions, and in appreciation of consequences.

Belter and Grisso, 1984-The 1984 study by Belter and Grisso studied the ability of 60 middleclass males ages 9, 15, and 21 to recognize a violation of their rights as patients in a simulated counseling session and to take steps to assert and protect their rights against violations by the professional (18). The research procedure involved half the participants at each age level receiving briefings on the rights of patients (e.g., the rights to refuse treatment, to know the reason for referral, to withhold information, to refuse to allow tape recording of the session, and the rights of confidentiality and access to records). In a subsequent session, participants observed a videotaped counseling session and were asked at various points whether or not a right was being violated and, if so, what they would do to protect the right.

The Belter and Grisso study found that 15-year-olds did not differ from 21 -year-olds in their scores on the recognition or protection of rights or in the benefit they gained from the briefings about patients' rights. On the other hand, this study found that 9-year-olds showed significantly lower recognition of or asserted protection of rights than did the 15- or 21-year-olds, who did not differ from each other.

Kaser-Boyd et al., 1985—The 1985 study by Kaser-Boyd et al. compared behaviorally disordered, emotionally disturbed, and learning disabled individuals ages 10 to 13 to those ages 14 to 20 in their ability to assess risks and benefits of psychological treatment (48).

This study found that the 10- to 13-year-olds did not differ from the 14- to 20-year-olds in the identification of risks or evaluation of eight benefit

dimensions. A serious problem noted by the authors, however, is that in some of these comparisons, the numbers were too small to permit a significance test to be performed. In terms of differences in decision-making as a function of age, this study found that participants ages 14 to 20 identified more potential benefits from psychotherapy and expressed the perceived benefits in more abstract terms than participants ages 10 to 13.

Kaser-Boyd et al., 1986--The 1986 study by Kaser-Boyd et al. asked 75 adolescents ages 10 to 19 with mild to severe learning and behavior problems to distinguish among risk and benefit factors, as well as irrelevant considerations, with respect to a hypothetical decision to acceptor refuse psychotherapy (49). One might regard the decisionmaking ability of a group of adolescents with problems such as these as immediately suspect, but in fact a group such as this may be the right group of adolescents to be testing, because it is adolescents with problems such as theirs who might actually be asked to decide whether to accept psychotherapy. Although this study does provide comparisons in decisionmaking among younger and older study participants up to 19 years of age, it does not provide comparisons between subjects with and subjects without the problems mentioned.

In any event, this study found no differences in decisionmaking as a function of age. Participants ranging in age from 10 to 19 years of age showed no differences in distinguishing risks, benefits, and irrelevant considerations, or in the psychological treatment decisions they made.

Ambuel, 1989—The 1989 study by Ambuel collected and analyzed data from 75 socioeconomically diverse females ages 13 to 21 who suspected an unplanned pregnancy and were visiting a medical clinic for a pregnancy test (1). This study is noteworthy for combining a real-world setting in which research participants faced a potentially serious and stressful decision with extensive and careful measurement of attitudes, affect, and cognition.

The study found that-apart from females ages 13 to 15 who said they excluded abortion as an option—participants showed no age-related differences in three measures of cognitive competence (thoroughness of consideration of consequences, number of reasons considered, and quality of the

process and content of reasoning about pregnancy) or in a measure of "volitional competence."

Females ages 13 to 15 who did not consider abortion as an option (but no other groups of minors, categorized either by age or attitude toward abortion) had significantly lower scores than adults age 21 and under on every measure of competence except one measure of cognitive competence (the number of reasons considered). This difference suggests that females ages 13 to 15 who regard abortion as a possibility have cognitive and volitional competencies similar to or indistinguishable from those of young adult females, whereas females age 13 and above whose competencies are lower have ruled abortion out and are therefore not likely to seek an abortion anyway.

Findings of Other Studies on the Age-Competence Relationship in Health Care Decisionmaking

The finding of several studies that are not part of the core group discussed above provide some additional insight concerning age-related similarities and differences in health decisionmaking.

Lewis et al., 1977—A 1977 study by Lewis et al. systematically observed the behavior of elementary school children ages 5 to 12 in an innovative program in two Los Angeles schools (58). That program allowed children to decide when a health problem required the attention of the school nurse, to sign themselves out of class to see the nurse, and to choose among treatment options presented to them by the nurse. In short, the program allowed the children the same freedom as adults in making their own health care choices, and the children's choices had real consequences for treatment.

The authors of this study found that children in their school's self-activated health program made sensible (even in adult terms) use of their power to choose. It is interesting to note that the elementary school children in this study are below the age at which we would have any theoretical reason based on developmental psychology to expect equivalence between child and adult decisonmaking.

Lewis et al., 1978-A 1978 study by Lewis et al. invited 213 elementary school children ages 6 to 9, grouped in their classes, to become informed about swine flu vaccine trials and to decide whether or not

to volunteer to participate (57). If a child did volunteer, the consent of the child's parents was sought, and if granted, the child did participate in the vaccine trial. Thus, the child's decision had potential real consequences.

This study found very few age-related differences in the ability of classes of children to elicit information about the flu and the vaccine and about potential risks and benefits of participation in a vaccine trial, although one class of 6-year-olds did not elicit all the relevant information it could have. It is important to note that this study really measured group ability rather than individual ability-to elicit information critical to making the decision to participate in medical research. If, as seems likely, there is significant variation in decisionmaking capacity among individuals within age groups, then measuring group ability would tend to minimize differences between age groups. In other words, assuming that the percentage of individuals who could think of all the questions to ask increases with age, then any of these groups might as groups be able to ask all the right questions and appear equally capable, while in fact important developmental changes were occurring over time (as larger and larger percentages of children in older classes would individually be able to ask the appropriate questions). The basic question before us pertains to the competence of minors as individuals and the information-seeking of individuals that is more typical of the informed consent process in our institutions. Still, it is striking that even in a group of 6-year-olds, there are enough group members that in all but one class all the relevant information was elicited by the children.

Kazdin, 1986---A 1986 study by Kazdin had parents and their severely disturbed children rate the acceptability of different kinds and settings of mental health treatment (51). This study found that parents rated both outpatient treatment and hospitalization as more acceptable than their children did. The parents rated hospitalization higher than outpatient treatment; the children rated them in the reverse order. Furthermore, the strength of treatment was positively correlated with acceptability for parents and negatively correlated for children. According to Kazdin, these differences may very well reflect differences in the meaning of the treatments for

parents (e.g., relief) and children (e.g., abandonment).

Grisso, 1981—An important note of caution is raised by a study that addresses not medical decisionmaking by minors but legal decisionmaking—Grisso's 1981 study of juveniles interrogated by police, with particular attention to the decisionmaking of these youths in asserting or waiving their legal rights (39). This study reminds us that minors making decisions in different contexts and different subsets of minors may show important differences in decisionmaking as compared with adults.

This study found that 42 percent of arrested adults chose not to answer police questions but that fewer than 10 percent of arrested juveniles asserted their right to remain silent-and virtually none of the arrested juveniles under age 15 refused to answer police questions. 39 As a group, juveniles under age 15 showed little comprehension of the Miranda warning 40—so little comprehension in fact that their decisions to assert or waive those rights had little meaning. Furthermore, as many as half of the iuveniles ages 15 to 16 who had IOs below 80 or who were black or in lower socioeconomic groups also showed little comprehension of their legal rights and the consequences of asserting or waiving their rights. This study found that white juveniles who had greater contact with juvenile courts and police evinced improved understanding of *Miranda* rights, but black juveniles who had such contact evinced poorer understanding. Greater contact with police and courts did, however, lead to greater understanding of the different roles of judges, lawyers, and police.41

Findings of Studies on How Variables Other Than Age Affect Adolescents' Health Care Decisionmaking

Variables other than age have important effects on decisionmaking, and several studies involving some of these other variables in the context of health decisionmaking by minors are described below. The studies reviewed here do not permit any definitive conclusions about how variables such as gender, socioeconomic status, race and ethnicity, intellec-

tual skills, experience, condition severity, pressure from peers or family, or skill training affect decisionmaking by minors. They do, however, point to areas in which the gathering of additional data about minors' decisionmaking capacity would probably be useful.

Gender-Only one core study reviewed by OTA's contractors specifically examined effects of gender on decisionmaking. That study, the 1982 study by Weithorn and Campbell, used equal numbers of male and female participants and found no gender differences in decisionmaking in hypothetical treatment situations (86). Two other studies that examined the effect of gender and were reviewed by OTA's contractors were the 1977 and 1978 studies by Lewis et al. The 1977 study by Lewis et al. reported that the patterns of utilization of health services by elementary school boys and girls (ages 5 to 12) participating in their school's self-activated health program paralleled the utilization patterns of adults—i.e., girls made more use of the services than boys (58). The 1978 study by Lewis et al. reported that elementary school boys and girls ages 6 to 9 did not differ in the questions they asked after being invited to volunteer for swine flu trials, but reported both that boys volunteered less often than girls and that girls more often than boys found themselves unable to make a choice about volunteering.

Socioeconomic Status-None of the core studies reviewed by OTA's contractors examined the effect of socioeconomic status on decisionmaking, but decisionmaking by minors from different socioeconomic groups was compared in one of the other studies they reviewed. That study, the 1977 Lewis et al. study, found that the poorer elementary school children (ages 5 to 12) in their school's selfactivated health program made more visits to the school health service than the more affluent children (58). Furthermore, the poorer children saw their health as more in the control of physicians, while the more affluent children saw their health as being more influenced by forces that they themselves could control. None of the other studies OTA's contractors reviewed had enough minors from lower socioeconomic strata to allow conclusions about

³⁹The U.S. Supreme Court has found juveniles t. be competent to make their own decisions in this context and has held such waiver of constitutional rights by minors to be valid [Fare v. Michael C., 442 U.S. 707 (1979)].

⁴⁰The Miranda warning is the standard warning given to apprise criminal suspects of their constitutional rights in regard to custodial interrogation by police--they have the right not to answer any questions and the right to the advice and assistance of an attorney.

⁴¹For a discussion of adolescents in the juvenile justice system, see ch.13, "Delinquency: Prevention and Services," in Vol. II.

possible differences in decisionmaking related to socioeconomic status.⁴²

Race and Ethnicity--only one of the core studies OTA's contractors reviewed reported on the effect of race or ethnicity on decisionmaking by adolescents. That study, the 1986 Kaser-Boyd et al. study among adolescents with mild to severe learning and behavior problems, reported that white, non-Hispanic adolescents obtained higher scores on the psychological treatment decision vignettes than other participants; but only 14 of the 75 subjects in this study were black or Hispanic (49). The 1977 Lewis et al. study reported that as white elementary school children gained experience in their selfactivated health program, they increasingly saw themselves as the decisionmakers, but that the same shift did not occur for the black or Hispanic children (58).

Intellectual Skills-Only one of the core studies OTA's contractors reviewed, the 1986 study by Kaser-Boyd et al., compared participants with different intelligence or a comparable measure of intellectual ability (49). This study found, unsurprisingly, that participants with poor reading comprehension scored less well on the decision tasks. A point made earlier in this discussion was that there seems to be considerable variation in decisionmaking ability of individuals within particular age groups. This within-group variation could be due to a variable that is more important to the quality of decisionmaking than age. Intelligence or reading comprehension may very well be that variable, but few data on this topic have been collected.

Experience-Only two of the core studies OTA's contractors reviewed examined the effect of experience on decisionmaking. The 1986 study by Kaser-Boyd et al. found surprisingly that participants with learning and behavioral problems who had had experience with psychotherapy obtained lower scores on the psychological treatment decision vignettes than participants without such experience (49). The researchers advanced several hypotheses to account for this finding. The 1985 study by Kaser-Boyd et al. found that participants with learning, behavioral, and emotional problems who had experience with psychotherapy were more likely than participants who had no experience to assert

that psychotherapy had low risks and that participants who were currently referred to therapy saw somewhat more benefits to psychotherapy than participants who were not referred (48).

No other studies of which OTA is aware make comparisons among experienced and inexperienced decisionmakers. One would expect decisionmakers experienced with the decision domain to show some differences from those who are new to the decision domain. Presumably, one advantage that older—especially considerably older--decisionmakers have is experience with the decision task, and presumably some decisions benefit more from such experience than others. More research on this topic would probably be useful.

Condition Severity-Only one of the core studies OTA's contractors reviewed examined the effect of condition severity on competence to decide. This study, the 1986 study by Kaser-Boyd et al., found that participants not currently referred for psychological treatment and participants with moderate behavior problems scored higher on the psychological treatment decision vignettes than participants currently referred for psychological treatment and participants with severe behavior problems, respectively (49).

Two of the other core studies provide a partial answer to the question of whether the severity of a condition that does not impair a decisionmaker's intellectual functioning affects decisionmaking, the 1982 study by Weithorn and Campbell (86) and the 1981 study by Lewis (56). These two studies, which presented to participants several different treatment dilemmas varying in seriousness, reported no systematic differences in decisionmaking as a function of the seriousness of the condition.

Social Influence From Peers, Parents, or Professionals----one issue that often is raised, but seldom studied with care, is the ability of minors to make independent decisions not unduly influenced by peers, parents, or professionals. As far as one can tell, the issue of minors' ability to make decisions without undue influence from peers, parents, or professionals has not even benefited from a thoughtful conceptual analysis of the questions that need to be asked. When is a rejection of information from and about others evidence of independent judgment,

⁴²For a further discussion of issues Pertaining to the delivery of health and related services to adolescents living in poverty, as well as adolescents in specific cultural subgroups, see ch. 18, "Issues in the Delivery of Services to Selected Groups of Adolescents,'" in this volume.

and when is it a sign of irrationality? When is sensitivity to the ideas and conduct of others thoughtful open-mindedness, and when is it conformity? Does the tendency toward conformity vary with the context? These and many other questions remain to be answered.

None of the core studies OTA's contractors reviewed examined the relationship between age and conformity to social influence in decisionmaking. Available research on the general relationship of age and conformity to social influence suggests the relationship between age and conformity to social influence is complex. The available research shows inconsistent findings, which may be reconciled by positing that conformity to social influence decreases from ages 7 to 11, then increases from ages 11 to 13, and then begins to decrease after that. 43 A 1988 study by Scherer and Reppucci examined the effects of parental pressure on hypothetical health decisions by adolescents ages 14 and 15 and found that these adolescents yielded greatly to parental pressure (76). The Scherer and Repucci study found that the more consequential the health problem and invasive the treatment choices, the less the 14- and 15-year-olds yielded to parental pressure; the more socially sensitive the condition, the more these adolescents yielded to parental pressure.

Surely the amount of social conformity people exhibit varies widely with the social situation and setting as well as with the individual. In fact, it is at least conceivable that developmental effects on social conformity may actually be overshadowed by situational variables. On the other hand, there may be complex situation-by-development interactions. Studies to examine that possibility have yet to be done.

Skill Training-Only one of the core studies OTA's contractors reviewed examined the effect of skill training on competence to decide. In the 1984 Belter and Grisso study, half the participants at each age level received briefings on patient rights and half did not. This amounts to specific training in one aspect of decisionmaking by patients (18). Unsurprisingly, participants who received briefings

showed significantly higher recognition and protection scores than participants who did not. The 15- and 21-year-olds both derived significant benefit from the briefing, but the 9-year-olds did not derive any benefit. With the briefings, the 15-year-olds performed indistinguishably from the 21-year-olds in the recognition and protection of their rights as patients.

None of the other core studies OTA's contractors reviewed involved special efforts to teach decision-making skills to minors. Some additional research has addressed the question of whether decisionmaking skills can be taught. For example, a 1988 study by Weinstein has prepared children for psychotherapy by using videotaped modeling (84), and a 1986 study by Haremes and Petersen has shown that sixth grade children can be taught resistance to persuasion and thereby taught to make more independent decisions (41). These studies suggest that even if minors were found to lack adult-level competence to consent—which in general they have not been—it might be possible to prepare minors to make decisions that reflect a heightened level of competence

Implications for Public Policy of Empirical Research on Minors' Competence

The studies that form the core of OTA's review on the age-competence relationship in health care decisionmaking, though not great in number, do provide at least some empirical support for the idea that minors as a class-especially minors age 14 or 15 through age 17—have the same capacity to make health care decisions as young adults. These empirical studies, therefore, challenge the traditional and implicit assumption of the law that minors as a class are unable to make health care decisions as well as adults. Furthermore, the studies' findings on this point are consistent with a huge body of research on cognitive development generally.⁴⁴

Are the empirical studies reviewed in this chapter sufficient to establish that adolescents as a group, ages 14 or 15 and above, are competent to consent to their own health care? Probably not. Beyond being

⁴³See P. Costanzo and M. Shaw, "Conformity as a Function of Age Level" (32); and B. Bishop and L. Beckman, "Developmental Conformity" (20).

⁴⁴See D. Elkind, "Conceptual OrientationShifts "Children and Adolescents" (34); J. Flavell, The Developmental Psychology of Jean Piaget (36) and "An Analysis of Cognitive-Developmental Sequences" (37); B. Inhelder and J. Piaget, The Growth of Logical Thinking From Childhood to Adolescence (46); D.P. Keating, "Thinking Processes in Adolescence" (52); G.B. Melton, G.P. Koocher, and M.J. Saks, Children's Competence To Consent (63); and E.D. Neimark and N. Lewis, "Development of Logical Problem Solving: A One-Year Retest" (69).



Photo credit: U.S. Congress, Office of Technology Assessment

Available empirical research challenges the traditional and implicit assumption of the law that minors as a class are unable to make health care decisions as well as adults.

rather few in number, the studies reviewed leave gaps in the knowledge ideally needed for the formulation of public policy pertaining to adolescents' involvement in health care decisionmaking. One limitation of the available studies is that most of them did not examine minors' decisionmaking performance in situations sufficiently real and stressful to see what effects such situations may have on their decisionmaking performance (although the few that did examine this found the same pattern of results as the other studies). Another limitation of the available studies is that they generally compared minors' decisionmaking with the decisionmaking of very young adults rather than with that of adults of various ages. Still another limitation of available studies is that they leave open several important questions about the effects exerted on minors' decisionmaking by factors such as socioeconomic status, ethnicity, social influence, skill training, and

experience, and how these might interact with the age-competence relationship found in the generally white middle-class groups studied. It is difficult to know how well one may generalize from the groups studied to the groups not studied.

Two basic responses can be made to the limitations of existing studies of minors' health care decisionmaking capabilities. One would be to carry out studies designed to generate more complete data. The other would be to make judgments as to whether the pattern of findings of existing studies is firm enough to expect them to carry over into untested areas. Whatever is done, it is important to bear in mind that there is considerable variation among individual adolescents. Some of the empirical studies reviewed for this chapter *note the* great variation of performance within age groups, but they do not go beyond that. Because of individual variation in decisionmaking capacity among adolescents, some adolescents ages 14 and older do not, in fact, have the requisite capacity to make health care decisions. Even if the average minor of any given age group can make health care decisions as well as the average adult, if the variability is much greater among the minors than it is among adults, then a large absolute number of minors might fall below whatever the standard of competence is.

The problem of individual variation in decision-making capacity within an age group can be dealt with in various ways. One way would be for public policymakers to require individualized determinations of competency by courts or even by health professionals. Unfortunately, however, an approach based on individualized determinations would open the door to discriminatory and arbitrary determinations unless there were tests of decisionmaking capacity that were reliable and valid and that could be administered easily—and it is doubtful that there are such tests. Moreover, individualized determinations can be quite expensive in terms of resources.

Another way of dealing with the problem of individual variation in decisionmaking capacity would be for public policymakers to establish a rebuttable legal presumption of competence based on chronological age that could be used by courts to make individualized determinations of competence

⁴⁵Some observers suggest that not one of the usual tests of competence relied on by the law and health professional.% videncing a choice, reasonableness of outcome of choice, 'rational' reasons, ability to understand, actual understanding-is or can ever be used consistently and that changing circumstances and considerations modify the tests that the law or clinicians apply (74).

(31). 46 Thus, for example, public policymakers could establish a legal presumption that any minor age 14 or above is competent to make health care decisions, but could also allow for the use of evidence of an individual's inability to make such decisions to rebut that presumption. 47

Finally, it must be noted that considerations of minors' health care decisionmaking capacity have not been the sole determinant of the degree of freedom minors have been granted with respect to obtaining health services on their own. As pointed out earlier in this chapter, the presumption that minors are incompetent to make decisions about health care based on assumptions about minors' lack of health care decisionmaking capacity is only one of several rationales-albeit a major rationales--for parental consent and notification requirements. It also must be noted that only some of the recognized exceptions to parental consent and notification requirements are based on a rejection of this legal presumption and underlying assumptions. In short, the capacity of a minor to make health care decisions may be a necessary but not a sufficient condition for allowing a minor to obtain health services on his or her own. Conversely, the lack of capacity on the part of a minor to make health care decisions may not preclude allowing the minor to obtain health services without parental permission.

Conclusions and Policy Implications

This chapter began by asking how the law should allocate authority for making decisions about an adolescent's health care among the adolescent, the adolescent's parents, health professionals, and the state. It is important to emphasize that the way in which the law allocates adolescent health care decisionmaking authority does not become critical, or even very relevant, unless the adolescent and one or another of the parties just mentioned are in conflict. As noted earlier, however, potential or actual decisionmaking conflicts can and do sometimes occur. In the case of family planning and abortion services and possibly other types of health services that may be needed or wanted by adoles-

cents, parental consent and notification requirements may sometimes pose barriers to access.

The ultimate responsibility for deciding how the law should allocate authority for making decisions about an adolescent's health care rests with public policymakers-legislators, judges, and administrators of public programs. If public policymakers are to formulate appropriate public policy pertaining to the allocation of authority for adolescent health care decisionmaking, they must balance the interests of adolescents, parents, health care providers, and the state. 48 Balancing these interests is no easy task. especially when the balancing has to be done in a political environment in which policymakers must rely on value judgments about which there is no consensus. It is at least possible, however, that an analysis of the interests of the various parties involved can serve as a conceptual framework for the development of clearer, more rational, and more consistent policies. Such an analysis is presented in box 17-B.

Laws related to the allocation of authority for decisions about the provision of health services to minors-individuals under age 18 in 47 States and the District of Columbia, and under age 19 in 3 States—have historically been the province of State legislatures, State courts, and State administrative agencies. As noted in this chapter, existing State laws governing parental consent and notification for different types of health services vary widely from State to State, and the laws of a particular State often vary with respect to different types of services or situations. For the most part, therefore, existing State laws do not furnish clear and consistent answers to the question of how authority for minors' health care decisionmaking is allocated.

Given the array of laws and regulations described in this chapter, many adolescents-and perhaps even providers—are probably uncertain about how these laws and regulations pertain to them as individuals. The involvement of the U.S. Supreme Court and lower Federal courts in the allocation of authority for decisions about family planning and abortion services through their power to interpret the

⁴⁶See F.E. Zimring, The Changing Legal World of Adolescence (90).

⁴⁷See President's Coremission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, Making Health Care Decisions, Volume 1: Report (72).

⁴⁸See R. Bennett, "Allocation of Child Medical Care Decision-Making Authority: A Suggested Interest Analysis" (19); L.S. Ewald, "Medical Decision-Making for Children: An Analysis of Competing Interests" (35); M.S. Wald, "Children's Rights: A Framework for Analysis" (82); Harvard Law Review, "Developments in the Law—The Constitution and the Family" (42); and F.E. Zimring, The Changing Legal World of Adolescence (90).

Box 17-B—A Conceptual Framework To Aid Public Policymakers in Formulating Policy Related to the Allocation of Authority for Adolescent Health Care Decisionmaking

A conceptual framework to aid public policymakers in formulating policy related to the allocation of authority for adolescent health are decisionmaking can be supplied by analyzing the interests of the parties who maybe involved in such decisionmaking-namely, the adolescent, the adolescent's parents, the health care providers, and the state. The essential issue to be considered in such an analysis is: Does the state have an interest or interests derived from the interests of the adolescent, the adolescent's parents, or healthcare providers-or does the state have an independent interest-that would justify a particular allocation of authority for adolescent health care decisionmaking via statutes, judicial decisions, or administrative regulations?

Interests of the Adolescent and the State-An adolescent has obvious interests in protecting his or her own life and in maintaining good physical and mental health--interests that translate into an interest m timely access to needed health services. The state, under its parens patriae power, also has an interest in protecting the life and health of the adolescent and thus also has an interest in ensuring the adolescent's access to needed health services. The nature and extent of the adolescent's interest-and by extension the state's interest-in the adolescent's access to health services varies, depending on the type of service and circumstances. Clearly, the interest is greatest in the case of health services that are needed to preserve life (e.g., emergency medical services for a seriously injured or suicidal adolescent) and less in the case of health services that maybe viewed as desirable but are not necessary to preserve or even to achieve or maintain health (e.g., cosmetic surgery). In situations where the adolescent's life or health maybe at stake, the adolescent's interest in access to services should be paramount in any balancing of interests to arrive at an appropriate allocation of the authority to make decisions concerning the provision of health services to adolescents.

Given the interests of the adolescent and the state in ensuring that the adolescent has access to needed health services, an issue that arises is whether-and if so, to what degree-legally mandated parental consent and/or notification requirements create barriers to adolescents' access to services. Several empirical studies have found that such requirements do create barriers to adolescents' access to and utilization of family planning and abortion services (21,22,25,2628,78,79,87,88); the applicability of the findings of these studies to other types of services, however, remains unclear. If policymakers are considering the advisability of allowing adolescents to make their own health care decisions, a central concern becomes the competency of adolescents to make appropriate determinations as to their need for services. Some empirical studies, which are reviewed in this chapter, suggest that adolescents ages 14 or 15 and above have the same capacity to make health care decisions as young adults. It is important to bear in mind, however, that these studies have a number of limitations. Furthermore, adolescents within these age groups exhibit individual variation in decisionmaking capacity, and this variation itself has implications for public policy.

Interests of the Adolescent's Parents and the State-Parents and their minor children typically have affectional and other ties, and the parents of most adolescents are likely to have an interest in ensuring that decisions about the provision of health services for their adolescent child will benefit him or her. In some cases, however, an identity of interest between an adolescent and the adolescent's parents cannot be assume@ nor can it be assumed that the parents will always act in the adolescent's best interests in health care decisions affecting the adolescent. Parents have responsibility for the care, support, and rearing of their minor children, and the parents of an adolescent may have an interest in maintaining their authority over the adolescent. The parents also may have a more generalized interest in protecting their family's autonomy and privacy and in promoting their family's stability and cohesiveness.

The state may or may not have an interest in reinforcing parental authority. The state certainly has an interest in having the parents continue to assume responsibility for their adolescent child, however, and if parental authority is reduced, parents may be less willing to assume this responsibility. The state also has an interest in protecting family autonomy and privacy, which are widely valued in American society, but the protection of family autonomy and privacy is not necessarily the same as reinforcing parental authority. The state also has an interest in maintaining family cohesiveness and stability, but this is not necessarily the same as reinforcing parental authority.

Interests of Health Care Providers—The interests of health care providers are seldom discussed or even mentioned in discussions concerning the allocation of authority for adolescent health care decisionmaking. Certainly, however, health care providers can be said to have an interest in providing services to adolescents that

Continued on next page

Box 17-B—A Conceptual Framework To Aid Public Policymakers in Formulating Policy Related to the Allocation of Authority for Adolescent Health Care Decisionmaking-Continued

are consistent with their professional ethics (e.g., standards pertaining to confidentiality) and consistent with accepted professional practices. Providers have an interest in being able to receive compensation for services they provide. Providers also have a more narrow, but nonetheless significant interest, in clear and consistent laws to enable them to avoid unintentional violation of these laws. It is not clear, however, whether or to what degree the state has an interest m promoting or furthering these interests of health care providers.

Independent *Interests of the State--Although, to some* extent, the state's interests maybe derived from and substantially the same as those of the adolescent, the adolescent's parents, and health care providers, the state also has its own independent interests. Thus, the state has a clear independent interest in ensuring that adolescents are tested and treated for sexually transmitteddiseases to prevent the spread of those diseases and thereby protect its citizens from these diseases. To the extent that adolescent childbearing results in increased public expenditures for health and human service programs that seine families started when the parents were adolescents (e.g., public programs such as the Medicaid program, the Aid to Families With Dependent Children program, and the Food Stamp Program) and to the extent that adolescent childbearing is associated with negative health, educational, economic, and social consequences for these families, the state may also have an independent interest in ensuring access of adolescent to family planning services and abortion services.

Interests of the Various Parties Depending on the Types of Health Services Involved-The interests of the adolescent, the adolescent's parents, the state, and health care providers may well differ depending on the types of health services involved-and the way the interests are balanced may well differ depending on the types of services involved. Thus, analyzing the interests of the parties concerned may lead to rules regarding the proper allocation of authority for adolescent health care decisionmaking that vary for different types of services. What this means for policymakers is that while one set of rules may appropriately govern the allocation of decisionmaking authority for general medical cam, another set of rules may appropriatelygovern the allocation of Decisonmaking authority for family planning services, another set of rules may govern the allocation of this authority for mental health services, and still another set of rules may govern the allocation of this authority for substance abuse treatment and counseling.

1 Various studies have different findin(considering the consequences of adolescent childbearing (38,54,80,89). For a further discussion of this topic, see ch. 10, "Pregnancy and Parenting: <u>Prevention and Services</u>," in Vol. II.

provisions of the U.S. Constitution may very well add to their uncertainties. One way of reducing adolescents' uncertainties, apart from moving laws toward greater uniformity, would be to incorporate information about the legal aspects of access to health services for adolescents in health education courses offered to adolescents in a State. Such information would give adolescents the information they need to make choices about whether or not to seek care.

Responsibility for allocating authority for health care decisionmaking now rests primarily with the State courts and legislatures and Federal courts. If it chose to, however, the U.S. Congress could play a greater role in formulating public policies pertaining to the allocation of authority for adolescent health

care decisionmaking. At least in theory, Congress may enact legislation that would have the effect of establishing particular substantive policies in this area at the State and local level.⁴⁹

One way for Congress to take on a larger role in formulating public policies pertaining to the allocation of authority for adolescent health care decision-making would be to enact legislation conditioning States' receipt of Federal funds for specified purposes on the States' having statutes or administrative rules and regulations that incorporate particular substantive policies with respect to health care decisionmaking for and by adolescents. To OTA's knowledge, this approach has not been used by Congress in this realm to date.

An alternative way for Congress to expand its role would be to enact legislation that requires federally funded programs that support the provision of health services for adolescents to adopt particular substantive policies with respect to the allocation of authority for adolescent health care decisionmaking, Congress authorizes and appropriates funds for a variety of programs that provide reimbursement or grants for adolescent health services-for example,

- . the Medicaid program authorized under Title XIX of the Social Security Act,
- the maternal and child health services block grant programs authorized under Title V of the Social Security Act,
- the family planning services and research program authorized under Title X of the Public Health Service Act, and
- the alcohol, drug abuse, and mental health services block grant program authorized under Title XIX of the Public Health Service Act.

The Federal laws authorizing and appropriating funds for these programs and the regulations and rules issued by the agencies administering these programs at the Federal level generally do not deal directly with questions of whether adolescents must have parental consent to participate in the programs, whether parents must be notified of adolescents' participation in the programs, or whether health care records and communications between program service providers and adolescents are confidential vis-ávis their parents.⁵¹ In the absence of explicit directives from Congress or Federal agencies, the administrators of federally funded programs are free-so long as they remain within the parameters imposed by State law and Federal constitutional law-to establish their own policies regarding parental consent and notification requirements and the confidentiality of records and communications involving minors.

If Congress were to legislate in the area of parental consent and notification and confidentiality of communications involving adolescents, it presumably would move laws governing matters such as parental consent and notification toward greater uniformity and coherence. Assuming for the sake of argument that greater uniformity and coherence is desirable, there remains the issue of what substantive policies Congress should adopt. That is a political judgment-some people would undoubtedly support requiring or encouraging parental involvement in decisions concerning health services for adolescents and others would support giving adolescents a substantial measure of autonomy in such decisions. To help guide policy makers in decisions governing the allocation of authority for health care decisionmaking, further empirical research on the decisionmaking capabilities of adolescents and factors that may influence these capabilities (e.g., age, prior experience, situational factors, intelligence) would probably be useful.

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⁵⁰ Some of these Federal programs are discussed in other chapters of this report. Medicaid, for example, is discussed in ch. 16, "Financial Access to Health Services." The Title X family planning program is discussed in Vol. II in ch. 10, "Pregnancy and Parenting: Prevention and Services." The maternal and child health services block grant program is discussed to some extent in ch. 9, 'AIDS and Other Sexually Transmitted Diseases: Prevention and Services." The alcohol, drug abuse, and mental health services block grant program is discussed in ch. 11, "Mental Health Problems: Prevention and Services, 'and ch. 12, 'Alcohol, Tobacco, and Drug Abuse: Prevention and Services.' A number of these programs are also discussed inch. 19, "The Role of Federal Agencies in Adolescent Health," in this volume.

⁵¹There have been some exceptions, for example, the previously discussed fii rule issued by the U.S. Department of Health and Human Services in 1987, which prohibits federally funded alcohol or drug abuse programs from notifying a minor's parent of the minor's application for treatment without the minor's consent but only in States where State law permits minors to obtain alcohol or drug treatment without parental consent [42 CFR, Part 22.14 (1989)].

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