Protecting confidentiality to safeguard adolescents’ health: finding common ground

Parents want their adolescent children to be healthy and safe; and society wants healthy adolescents who will grow into healthy adults. These statements may be truisms, but they are essential to recognize in the ongoing debates about confidential health services for adolescents. In spite of broad consistency among health care professional guidelines, research findings and legal protections, the debates continue. Too often the dialogue deteriorates into a harangue, even though there is much room for agreement among the vast majority of parents, policymakers and health care professionals. Advocates on both sides — proponents of confidential care for adolescents and supporters of mandated parental involvement — both claim the high ground but rarely find common ground. This must change. For that to happen, more attention needs to focus on the ways in which the interests of adolescents, parents, health care providers and society coincide rather than conflict.

Current efforts to limit confidentiality protections for adolescent health care, and particularly for sexual and reproductive health services, originated with laws first enacted three decades ago. Since that time, most states — with California and a handful of others being notable exceptions — have been successful in restricting access to abortion by minors without parental consent, parental notification or involvement by a court. Although the issue of confidential access to abortion for adolescents has been the most visible and the most frequently litigated, ongoing efforts to limit access to other confidential sexual and reproductive health care — for birth control and even STD services — have been deliberated and determined in Congress and numerous state legislatures. When these efforts have not succeeded, the reason has often been that parents who want their adolescents to be healthy and safe are helped to understand that restricting confidential care will put adolescents’ health and safety at risk rather than furthering them. This approach was recently effective in California in defeating a ballot proposition that would have amended the state constitution to require parental notification for minors’ abortions.

There is no doubt that the notion of requiring parental consent or notification for adolescents’ health care — especially when that care is related to sexual or reproductive health — seems initially appealing to many parents and policymakers [1]. Even the most sanguine parents may feel that requiring their consent for health care for their adolescent is beneficent given the frequent recitation of frightening statistics about STDs and teen pregnancy and youth violence — even though the “epidemic” aspects of these problems is often overstated by the media. There are other reasons that mandates for parental involvement may seem appealing: some parents worry about losing control as their children move into adolescence; while others believe it is their right to be involved. Ultimately, however, many parents come to understand the importance of confidential care when they learn that it will not only help to protect their children’s health but also help them learn to make responsible decisions as they move towards adulthood [2,3].

Providing confidential care to adolescents is consistent with what we know about adolescent development, what we can learn from research about the effect of limiting confidentiality, what is embodied in health care professionals’ ethical guidelines and policies, and what the law requires.

1. Learning to make independent health care decisions is consistent with healthy adolescent development

Those of us in the health field who care for adolescents have a responsibility to share what we know about adolescent development with parents who are trying to raise healthy young people. Beginning to make important health care decisions is helpful to adolescents for many reasons. Most 15, 16 and 17 year-olds — and in some cases younger teens — are cognitively and emotionally mature enough to understand the consequences of their actions regarding health concerns and are capable of giving informed consent to health care [4,5]. Permitting and encouraging them to do so with trusted health care professionals helps them develop the skills needed to become healthy adults.

Some parents, and some adolescents, have difficulty letting go of close parental involvement in health care decisions even after adolescents have become adults. Many health care professionals caring for college students are
familiar with the phenomenon of “helicopter parents” hovering over children who are legally adults, but who often abdicate important decisions to their parents rather than take responsibility themselves. Assisting young people during adolescence to begin developing the capacity to make their own decisions about health care, with guidance from trusted professionals and other adults, can serve them well as they enter adulthood and need to act responsibly and independently with respect to their own health care [2].

Failing to help young people acquire these skills can impede their developing the ability to make sound health care decisions and retard their essential maturation process of becoming a healthy adult. As health care professionals, we can and should help caring parents foster healthy development in their teenagers by aiding them in understanding that to raise responsible future citizens who can function in a complex society without constant parental assistance, they must give adolescents increasing responsibility at the appropriate developmental stages.

2. Research findings support the importance of confidentiality in adolescent care

A body of research conducted over the past few decades has consistently found that privacy is a significant concern for adolescents and that privacy concerns influence many aspects of their interactions with the health care system [6–8]. Concerns about whether care will be confidential — and specifically whether their parents will be informed — can determine whether adolescents forgo care entirely [9,10], which providers and sites they visit [11,12], whether they are candid in disclosing their health history [13] and which services they will accept [14–16].

The full picture as portrayed by the evidence from research is complex and nuanced, particularly with respect to sexual and reproductive health services. On the one hand, several studies have documented that a majority of adolescents using family planning clinics do so with their parents’ knowledge, or even at their explicit suggestion [17,18]. On the other hand, many adolescents say they would not use the clinic or would avoid certain services if their parents had to be notified [17,19]. Moreover, the vast majority of adolescents will not modify their health behaviors as a result of mandated parental notification — only 1% would stop having sex if parental notification were mandated for contraception, for example, and two in 10 would forgo contraception entirely or would rely on the withdrawal method [17]. Of minors whose parents did not know they were at the clinic, 70% said they would not use the clinic for prescription contraception if parental notification were required [17].

The impact on health outcomes of decreases in confidentiality protection has not been extensively studied, but the available evidence suggests that adverse effects are likely. For example, a study of Texas policies to require parental consent for state-funded family planning services and to increase reporting of adolescents sexual activity estimated that public costs for increases in teen pregnancies and STDs could be as high as $44 million annually [20]. An Illinois study examined the effects of one county’s implementation of a parental consent requirement for contraception and found an increase in the proportion of births to females under age 19 in that county, despite a decrease during the same period in nearby counties that had similar racial and economic profiles and no restrictions on minors’ access to contraception [21].

Although there is no sufficient evidence available “to make generalizations about the impact of [mandatory parental involvement] policies on teen pregnancy rates at this point,” there is also “little empirical support for the proposition that family planning clinics increase the sexual activity level of adolescents. And there is no research that supports the notion that mandatory parental involvement for either contraceptive services or abortion improves parent–child communication or facilitates conversations about sex, birth control or related matters” [22].

The impact of mandated parental involvement appears to be significant and potentially risky for adolescents’ health. Nevertheless, most adolescents seek health care — including sexual and reproductive health services — with their parents’ knowledge. So, it is essential for parents, policymakers and health care professionals to understand that not all adolescents require confidential care at all times; indeed, many share information with their parents. But for those who do need confidentiality protections at some point in their adolescence, or for specific services, those protections need to be in place.

3. Health care professionals support the importance of confidentiality in adolescents care

The importance of confidentiality in adolescent health care has long been recognized by health care professionals. Virtually every organization of health care professionals has incorporated into its policies and codes of ethics statements about the need to protect confidentiality in health care generally, the important role it plays in adolescent care and the kinds of protections that are needed for specific services and for special populations of adolescents [23]. The consistency among these statements is remarkable and reflects both an appreciation of the research findings and an awareness of the legal framework.

4. The legal framework provides confidentiality protections for adolescents

An extensive body of laws has been developed over the past half century that supports adolescents’ access to confidential health care based on their own consent. The
existing legal framework includes constitutional protections at the federal and state level, requirements of federal funding programs, privacy regulations issued under the federal Health Insurance Portability and Accountability Act that are often referred to as the HIPAA Privacy Rule, and elements of minor consent and medical privacy laws delineated by the states.

In a series of decisions dating back more than 30 years, the constitutional right of privacy has been held to protect minors as well as adults [24,25]. Specifically, the right of privacy protects minors’ decisions whether to “bear or beget” a child and extends to both contraception and abortion. Although minors’ right of privacy is not absolute and the state has greater authority to control the conduct of children and restrict their privacy than it can for adults, the protections currently in place are significant [26]. Supreme Court rulings have determined that a state may not require parental consent or notification for abortion without providing an alternative such as a judicial bypass that allows mature minors to make their own decision without involving their parents [26]. A state is also limited in the extent to which it can constitutionally restrict minors’ access to contraceptives [25,27]. Similar, and in some instances greater, protections for adolescents’ privacy rights have also been found in state constitutions.

Two federal programs that provide funding for family planning services have long protected confidential access for adolescents. Since 1970, the federal Title X Family Planning Program has provided confidential family planning services to low-income women and adolescents [28]. The Title X regulations contain strong confidentiality protections and these extend to adolescents as well as adults [29]. Efforts by states to require parental consent for Title X-funded services have been struck down by the courts [30]. Sexually active adolescents who are eligible for Medicaid also have a right to receive family planning services on a confidential basis [31]. Federal Medicaid law precludes states from requiring parental consent for minors to access family planning services [32].

The federal HIPAA Privacy Rule also protects minors as well as adults [6]. Minors who are legally able to consent for their own health care are generally treated by the Rule as individuals who are protected in their own right [6]. However, on the issue of parents’ access to their children’s protected health information, the HIPAA Privacy Rule defers to “state or other applicable law” [6]. Thus, to the extent that minors’ confidentiality is protected by specific state or federal laws — such as the myriad state minor consent laws that exist in every state, the medical privacy laws in some states, or Title X and Medicaid — it is protected by HIPAA also [6]. However, to the extent that, for example, state laws are silent or explicitly allow health care professionals to disclose information to parents, the HIPAA Privacy Rule allows that to occur [6]. In such circumstances, the discretion of the health care professionals should be guided not only by the legal framework, but also by the policies and ethical guidelines of health care professional organizations, the findings from research and their knowledge of adolescent development. Doing so will enable them to strike an appropriate balance between protecting adolescents’ interest in confidentiality and involving parents when that is necessary to protect adolescents’ health. Indeed, the commentary in the preamble to the HIPAA Privacy Rule explicitly states that it “does not want to interfere with the professional requirements...or other ethical codes of health care providers with respect to the confidentiality of health information or with the health care practices of such providers with respect to adolescent health care” [6].

5. Conclusion

Looking back over the past half century and reviewing the research findings about the effect of limiting confidentiality on health-seeking behaviors and health outcomes for adolescents, together with the policies and ethical guidelines of health care professionals and the longstanding legal framework for confidentiality, we can see that there is a remarkable consensus about the important role of confidentiality protections in safeguarding the health of adolescents. Dedicated health care professionals who care for adolescents, concerned parents who are trying to raise adolescents to become healthy and safe adults, policymakers who are trying to further society’s interest in the development of productive and responsible citizens, and adolescents themselves, all essentially have common interests that can provide the basis for finding common ground in the ongoing public discussions about confidentiality in adolescent health care.

Scott J. Spear, MD
Affiliate Medical Director
Planned Parenthood of Arkansas and Eastern Oklahoma
125 E. Township St., Suite 1, Fayetteville, AR 72703, USA
E-mail address: scott.spear@ppaeo.org

Abigail English, JD
Director
Center for Adolescent Health & the Law
310 Kildaire Road, Suite 100
Chapel Hill, NC 27516, USA
E-mail address: english@cahl.org

References


42 U.S.C. §§ 300 et seq.

42 C.F.R. § 59.11.

