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Who Needs to Know? Confidentiality in Adolescent Sexual Health Care

by Karen Schantz

This information is between us. Anything you tell me is confidential, which means that we will not inform your parents or anyone else without your consent. I would only tell someone else if I thought you had been abused or hurt, or if I believed you were at serious risk of harming yourself or someone else. If that were the case and I needed to talk to someone else, I would first talk to you and we would make a plan together.

Adolescents seeking sexual and reproductive health care are likely to hear a version of this speech—but does it fully address their privacy concerns? What does confidential care mean in practice, and can it be improved to meet young people's needs? In view of rising rates of sexually transmitted disease (STD) among young people, ACT for Youth reviewed recent research to update our understanding of the importance and practice of confidentiality for adolescents seeking sexual and reproductive health care.

How do adolescents view confidentiality?

Concern about confidentiality is *the most important barrier to care* for adolescents (Bender & Fulbright, 2013). In surveys and focus groups asking young people about their views of health care, confidentiality turns up again and again as a key indicator, especially in sexual health settings (Ambresin et al., 2013; Daley, Polifroni, & Sadler, 2017).

Who is going to know my business?

While many researchers and physicians conceive of confidentiality as consultation without a parent present, adolescents' privacy concerns are much broader and more nuanced. For teens, newly dealing with sexuality and highly sensitive to the stigmas associated with sex, the craving for privacy extends

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every step of the way from the clinic location to follow-up communications about test results (Bender & Fulbright, 2013).

Walking into a facility that provides sexual health care, young people often assess each person they see: *We're so close to my school—will anyone I know see me go in here? Isn't that receptionist a friend of my mother's? Is that stranger in the waiting room judging me because of my age? Does everyone know why I'm here? Who is going to find out that information, and what will they think of me?* The entire experience may be fraught with fear of being judged, labeled, embarrassed, or exposed:

- **In the waiting room**. Young people don't want to have to announce why they are at a clinic if they can be overheard in a waiting room (Britto, Tivorsak, & Slap, 2010). Adolescent girls fear for their reputation (Bender & Fulbright, 2013). For young males, the fear of being seen or overheard in a clinic that tests for STDs often stems from the fear that they will lose social status (Garcia et al., 2014; Marcell et al., 2017).
- **In the exam room**. Revealing information about sexual behavior even to clinicians can be difficult for adolescents, who fear that they will be judged (Britto, Tivorsak, & Slap, 2010; Cuffe et al., 2016). Lesbian, gay, bisexual, transgender, queer, and questioning (LGBTQ) youth in particular may need several visits before they trust the clinician enough to reveal their sexual orientation or gender identity (Marcell, Burstein, & AAP Committee on Adolescence, 2017). Young people's keen sense of privacy is also challenged by physical exams. For example, males are uncomfortable with having their genitals touched during an exam (Garcia et al., 2014).
- **Through their medical records**. Young people want their medical records, including any surveys they complete, to be kept confidential even from other health center staff—and they do not trust that this is the case (Daley, Polifroni, & Sadler, 2017; Rubin et al., 2010).
- **Through billing**. Teens are aware—and concerned—that visits for sexual and reproductive health care may be exposed to parents through insurance explanation of benefits forms (Shannon & Klausner, 2018).
- **Through partner notification regarding STD test results**. Males are concerned about how their partners will learn about a positive test result (Garcia et al., 2014).

While much of this anxiety is driven by the fear of parents finding out about a teen's search for birth control or STD care, clearly parents are not the only people teens want out of their business. In fact, in a general health care setting younger adolescents may be less concerned about parents, whom they may see as protective and calming, than about having their bodies seen and touched by clinicians and having their personal information shared with other providers (Britto et al., 2010).

Why do confidentiality fears matter?

Accommodating young people's confidentiality concerns is no small task. Parents understandably want to know about and influence the life decisions their adolescent children are making, and the push-pull of supporting adolescent "children" while allowing them to grow in independence is notoriously challenging. Likewise, for

health care providers, changing routines and systems is a complex undertaking. Even ensuring that everyone in the medical setting understands the difference between consent to care and confidentiality can be difficult (see sidebar; Wadman et al., 2014). However, the cost of ignoring adolescents' anxiety over confidentiality is high.

Confidentiality fears lead to missed or delayed health care

Too often, teens who are concerned about confidentiality delay getting the health care they need—or avoid it all together (Baldridge & Symes, 2018; Bender & Fulbright, 2013; Copen, Dittus, & Leichliter, 2016; Fuentes et al., 2018; Leichliter, Copen, & Dittus, 2017).

One large, nationally representative study found that nearly one in five teens age 15-17 said they would not seek sexual health care because their parents might find out (Fuentes et al., 2018). Those who were privately insured were especially likely to express this level of concern about confidentiality. Youth in this age group who do not live with a parent are even more at risk; over one in four of these adolescents would avoid getting care because of the fear that parents could find out. Similarly, nearly one in four sexually experienced teens this age—arguably those with the greatest need—would not seek care due to confidentiality concerns (Leichliter, Copen, & Dittus, 2017).

Despite runaway rates of STDs, many sexually active young people age 15-25 have not been tested (Cuffe et al., 2016). While confidentiality concerns don't entirely explain this lack of testing, they are a contributing factor. For example, sexually experienced adolescent and young adult women are less likely to be screened for chlamydia if they have concerns about confidentiality than their counterparts without such concerns (Leichliter, Copen, & Dittus, 2017).

Consent to Care vs. Confidentiality

Consent in the medical context refers to the provider's obligation to obtain informed consent before providing health services. While parents often consent to (i.e., authorize) services provided to their children, many states allow minors to consent to their own care when it comes to certain sensitive services such as sexual and mental health care.

Confidentiality refers to the protection of information exchanged between the health care provider and patient.

Depending on the state in which they live, adolescents are able to consent to certain sexual health care services on their own behalf, but this does not in itself guarantee confidentiality. For example, while a minor may consent to STD treatment, in some states the health care provider is permitted to notify the parents.

Widespread restrictions on confidential abortion services (see below) have negative consequences for young women's health. In reaffirming their position favoring confidentiality for adolescents considering abortion, the American Academy of Pediatrics (AAP, 2017) called mandatory parental notification laws "damaging," noting that they cause delays that push abortions weeks later into the pregnancy. Adolescents are typically slower than others facing an unintended pregnancy to 1) recognize that they are pregnant and 2) seek abortion services (AAP, 2017). While abortion in the first trimester is a very safe, same-day procedure, later abortions can be more risky and are certainly more expensive (AAP, 2017). There is also evidence that teens' inability to obtain confidential abortion services (due to the distance they would have to travel to reach a state that does not have mandatory parent notification laws) was responsible for a nearly 3% increase in births to teens from 1993-2014 (Myers & Ladd, 2017).

Confidentiality fears may lead young people to lie or suppress information

When adolescents do get health care, they may lie when asked sensitive questions in front of a parent (Daley, Polifroni, & Sadler, 2017; Fuzzell et al., 2016). Clinicians

who do not know the truth about risk behaviors cannot provide the care their patients need.

Adolescent fears may be well founded

Adolescents may have more to fear from confidentiality breaches than an awkward conversation with their parents. For some adolescents, fears of exposure are founded in the realities of their lives: parents and guardians who threaten violence or abandonment if a teen has sex, becomes pregnant, or is outed as LGBTQ; peers who bully, label, ostracize, or are violent toward young people who appear to be queer or otherwise violate the dominant culture. Similarly, some youth fear exposure to partners. A young woman may seek birth control, for example, knowing that her partner wants her to become pregnant and might become abusive if he knew of her plans to prevent pregnancy.

These fears may not be disclosed to the clinician. Rather, health care providers must trust that their patients are "the experts in their own lives" and respectfully support the desire for confidentiality as legitimate.

Pregnant minors may also need prenatal care. A Child Trends study (2018) found that over one in four girls younger than fifteen who gave birth in 2016 received late prenatal care—or no prenatal care at all. Young age is associated with inadequate prenatal care, which in turn is strongly correlated with premature birth (Debiec et al., 2010).

Confidentiality in Practice

Health care professions have long acknowledged the importance of confidentiality for adolescents. While recognizing that adolescents should always be encouraged to involve a parent or another trusted adult in their health care decisions, many medical associations consider the provision of confidential service an evidence-based best practice, and it is regularly included in service assessments (Mazur, Brindis, & Decker, 2018). Clinicians and researchers have pointed out that while it is essential to the present needs of young patients, confidentiality may also serve as part of a client-centered approach through which the practitioner builds a trusting relationship that can motivate regular use of the health care system throughout life (Gavin et al., 2014; Middleman & Olson, 2018). By offering and explaining confidential services repeatedly, clinicians make it more likely that adolescents will seek health care, talk about sensitive issues, and return for follow-up visits (Marcell, Burstein, & AAP Committee on Adolescence, 2017).

Likewise, relevant government agencies have acknowledged the critical nature of confidentiality. For example, the provision of confidential services has historically been a pillar of Title X federal family planning funding (Beeson et al., 2016). Confidentiality has also been identified by the CDC and the Office of Population Affairs as a "key step" for providing quality family planning services, especially for adolescents (Gavin et al., 2014).

However, from office policies that don't prioritize privacy, to laws that promote parental rights at the expense of minor children's health, to flawed medical records and billing systems, the health care experience is rife with potential confidentiality breaches.

Teens want answers—but may not have time alone with provider

Many young people today do want and often expect to have conversations about sexual health with health care providers (Córdova et al., 2018; Fuzzell et al., 2016). In some parts of the country this includes LGBTQ youth, who are ready to discuss sexual orientation and have questions about sexual health (see, for example, focus groups conducted in northern New Jersey; Snyder, Burack, & Petrova, 2017). However, adolescents want time alone with the clinician for these conversations, and too often this is not the case:

- A 2018 review of research found that over 40% of adolescents do not regularly have time alone with a provider for any kind of health service (Baldridge & Symes, 2018).
- Looking at nationally representative data with a focus on sexual and reproductive health services, Fuentes and colleagues (2018) found that among teens age 15-17 who had a health visit in the previous year, less than half (45%) had time alone with the provider.

Professional Associations Endorsing Confidential Care for Adolescents

American Academy of Family Physicians

American Academy of Pediatrics

American College of Obstetricians and Gynecologists

American Medical Association

American Public Health Association

Association of Women's Health, Obstetric and Neonatal Nurses

Society for Adolescent Health and Medicine

Legal Limits of Confidentiality

Health care providers cannot make unlimited promises of confidentiality. They must report the abuse of a minor, for example, which in some states could include consensual sex between an adult and a minor, depending on the age of the minor, the age difference between the adult and the minor, and whether the adult is in a caretaking role. Providers may also involve parents or others if they believe there is a risk of serious harm to the young patient or to another person, such as threats of suicide or homicide. State laws vary widely in their confidentiality protections and exceptions. Providers must be familiar with informed consent and confidentiality laws in their states as well as requirements that may be imposed by funders (Middleman & Olson, 2018).

STD Services. Currently, minors may consent to STD services—not always including HIV—in every state (visit the Guttmacher Institute for updated information: https://www.guttmacher.org/state-policy/explore/minors-access-sti-services). In some states, however, while a minor may legally consent to care for these services, the provider is nevertheless legally permitted to inform the parents (Guttmacher Institute, 2018a). In addition, states may mandate reporting of certain STDs to public health departments. Some states and cities also mandate that sex or needle-sharing partners be notified of positive HIV tests, and Ryan White HIV Program funding recipients must also attempt to notify a spouse (HIV.gov, 2017).

Contraceptive Services. Many states explicitly permit all minors to consent for contraceptive services. However, a few of these states allow health care providers to notify parents that their children are receiving these services. Other states permit minors to consent to contraceptive services only if they meet certain requirements (e.g., minors who are married, who are a certain age, have been pregnant, etc.); again, the ability to consent to services does not always mean those services will be confidential (Guttmacher Institute, 2018b).

Abortion Services. Most states restrict minors' right to confidential care when it comes to abortion services, generally requiring the consent of one or both of the

teen's parents (Guttmacher Institute, 2018c).

Prenatal Care. Most states explicitly allow a minor to receive prenatal care, though in some cases the minor must have reached a certain age or be judged mature enough to understand the treatment. Fourteen states, however, permit a doctor to notify parents that their child is receiving services (Guttmacher Institute, 2018d).

Pharmacist Refusal. In some states, even when a teen has received confidential care, pharmacists may refuse to fill prescriptions unless a parent is notified (Middleman & Olson, 2018).

Threats to Confidentiality

Middleman & Olson (2018) distinguish between the known exceptions to confidentiality, such as the legal limitations described above, and unintentional threats to confidentiality. An adolescent's private information may be inadvertently disclosed to parents and others through system failures:

Medical Records. Providers must document medical visits, and some records may include confidential information without identifying it as such. Electronic records and digital reminders also pose threats to patient privacy.

- Parents may request their child's medical record when transferring to a new provider and receive the entire chart, including documentation of services that were meant to be confidential.
- In some states, parents are granted the right to see the entire record unless there is an explicit law keeping certain patient information private.
- Electronic records and patient portals may not be fully secure.
- Automated appointment and birth control reminders may inadvertently expose confidential information.
- Records may be shared with educational institutions that serve the adolescent. Parents have a right to review their child's educational record through the Family Educational Rights and Privacy Act (FERPA), and may discover confidential health care information through that process (Middleman & Olson, 2018).

Explanation of Benefits. Young people who use their parents' private insurance may find that the confidential services they have received are detailed in the explanation of benefits sent to parents. In contrast to private insurance, coverage through Medicaid and the Title X (federal) Family Planning Program is more likely to protect the confidentiality of adolescent patients.

Strategies to Improve Practice

Managing privacy issues, some of which may have to do with the physical office space and clinic flow, can be tricky. Young people want to be able to talk to clinicians about sexuality and their changing health care needs in private. They don't want to announce the reason for their visit in a waiting room or in front of staff who don't need to know (Garcia et al., 2014; Rubin et al., 2010). While these issues may not all be easily addressed, taking the time to examine clinic practices in light

of teens' experience and privacy needs may reveal opportunities for change.

Changes in communication practices may be more actionable.

- A **clear, written policy on confidentiality** that conforms to relevant laws and regulations will help providers, adolescents, and parents begin to get on the same page.
- Pediatricians can lay the groundwork for expectations of confidentiality and time alone by **discussing the issue with parents and their children as the teen years approach**, and then follow up by reserving at least part of each visit for **time alone with the adolescent**. Explaining the reasons for the confidentiality policy may be especially important for parents.
- Young people strongly believe that if they are accompanied by a parent, **the provider should be the one to ask the parent to leave** for part of the visit as a matter of course (Daley, Polifroni, & Sadler, 2017; Fuzzell et al., 2016), as well as the one who initiates any discussion of sexual orientation, behaviors, and health (Córdova et al., 2018; Snyder, Burack, & Petrova, 2017).
- Providers should **encourage young people to involve a parent** or, if that seems impossible, another trusted adult in their health care decisions.
- Youth and practitioners alike recommend that the **confidentiality policy should be emphasized routinely and repeatedly** to put their patients at ease and ensure that the policy is understood (Association of Women's Health, Obstetric, and Neonatal Nurses [AWHONN], 2017; Fuzzell et al., 2016).
- **Handouts** for young people and parents that clearly explain the confidentiality policy can support verbal communications.

Involve a Trusted Adult

There is widespread consensus that teens should not be left to make these decisions entirely on their own. The principle of confidentiality is frequently paired with the recommendation that the clinician encourage each adolescent seeking care to talk to a parent, guardian, or—if the young person feels this is impossible—another trusted adult. In some cases, the health care provider may become that trusted adult, if they have developed a relationship over time or are comfortable and skilled in working with adolescents.

Better training may also improve practice. Given the complex mix of ethics, laws, and policies relating to confidentiality, health care providers and staff are often confused about how to handle confidentiality issues (Wadman et al., 2014). Training is necessary for every staff member who comes into contact with the patient, from the front desk personnel to the clinician, as well as billing staff, and should be ongoing, not a one-time event (AWHONN, 2017; Williams & Taylor, 2016).

- The Adolescent Health Initiative at Michigan Medicine (2017) has made available free PowerPoint presentations, facilitator scripts, and follow-up materials for a brief "Sparks" training on confidentiality laws for certain western and mid-western states: http://www.umhs-adolescenthealth.org/improving-care/spark-trainings/confidentiality-laws/
- Consent and confidentiality laws in each state are tracked by the Guttmacher Institute, offering an excellent resource for trainers: https://www.guttmacher.org/united-states/teens/state-policies-teens

Careful attention to documentation, digital systems, and sharing of electronic records is necessary to protect confidentiality. The technological health care environment is still new and ever-changing, and the potential for breaching confidentiality in this environment is not always well understood. Providers must also be aware of complex and competing laws that regulate information sharing.

- Pointing out that electronic health record systems and patient portals have been designed to facilitate rather than restrict the flow of information, the Society for Adolescent Health and Medicine has called on vendors of these systems to improve privacy controls (Gray et al., 2014). Standards for health information technology have been identified by AAP (2016), among other professional organizations. Providers should make sure that they purchase systems that best enable the protection of confidential information.
- Some electronic record systems may have confidentiality capabilities that are not being fully utilized. Providers should ensure that these features are implemented and staff are trained in their use.
- As noted above, if records are shared with schools and become part of the education record, confidential health information may be passed on to parents through FERPA. School-based health centers, however, can protect this information by seeking a blanket parental permission for all of the services offered by the center, with the explicit understanding that some of these services are confidential. The patient's record, in this case, is kept separate from the educational record and is subject to HIPAA rather than FERPA (Middleman & Olson, 2018). Nevertheless, the state's parental notification laws will apply.
- Similarly, providers outside of school-based centers may wish to educate parents about the importance of confidentiality in adolescence and ask them to sign comprehensive services consent forms (Williams & Taylor, 2016).
- The problem of confidentiality breaches through explanation of benefits notices is increasingly being addressed through state legislation, though the majority of states do not have such laws on the books (Guttmacher Institute, 2018e).
- When adolescents with private health insurance are concerned about potential confidentiality breaches through explanation of benefit notices, their providers may refer them to Title X family planning centers, which are required to provide confidential services with few exceptions (Beeson et al., 2016; Gudeman & Madge, n.d.; Marcell, Burstein, & AAP Committee on Adolescence, 2017).

Final Thoughts

Confidentiality protections exist to encourage healthy decision-making. Without these protections, many adolescents will avoid or defer caring for their sexual health, and some will lie to their providers, despite the risk that they may face unwanted consequences as a result.

Respect for privacy is the root of a trusting relationship between health care provider

and patient. Health care providers may be privy to intimate and even secret details of their patients' lives. But for patients to open up about aspects of their lives that could potentially affect their health, they must be confident that those details will not be shared unnecessarily.

When adolescents are treated as independent, respected decision-makers, and at the same time receive the information and counseling needed to make health decisions, they are afforded the developmental support and room they need to grow into healthy adulthood. Confidentiality protections are central to this process.★

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ACT for Youth

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