

Confidentiality & Adolescent Health Care in a Changing World

Consent? HIPAA? FERPA? EOBs? EHRs?

Abigail English, JD
Center for Adolescent
Health & the Law
english@cahl.org

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Overview

- Rationale & research findings
- Ethical principles
- Legal framework
- Professional policies
- Confidentiality & insurance – EOBs
- EHRs & web portals
- Continuing controversies
- SBHC challenges & strategies

First Principles

- Comprehensive services
- Minors & adults
- Positive family involvement
- Lack of supportive families
- Laws & adolescent access to care

Parents and Adolescents

- Voluntary communication
 - Supportive parents
 - Adolescent disclosure
- Mandated communication
 - Dysfunctional families
 - Adolescent autonomy
- Interests of adolescents & parents

Rationale for Confidentiality Protection

- Avoid negative health outcomes
 - Protect health of adolescents
 - Protect public health
- Encourage adolescents to seek needed care
- Supported by research findings

Research Findings: Privacy Concerns

- Many adolescents have privacy concerns
- Adolescents are primarily concerned about disclosure of information to their parents related to
 - sexual behaviors
 - substance use
 - mental health

Research Findings: Effect on Behavior

- Privacy concerns can influence:
 - Whether adolescents seek care
 - Foregone care
 - When adolescents seek care
 - Delay
 - Where adolescents seek care
 - Choice of provider
 - How openly adolescents talk with health care provider
 - Candid health history

Research Findings: Parental Knowledge

- Likely parental knowledge or mandated notification
 - Decreased willingness to be tested for STDs
 - Increased likelihood of stopping use of all sexual health services
 - Increased likelihood of stopping use of clinic
 - Minimal likelihood of stopping sexual activity

Research Findings: Outcomes & Cost

- Texas study of projected costs due to loss of confidentiality in publicly funded clinics
 - Increased pregnancies, births, abortions, and untreated STDs
 - Projected annual increased costs > \$43 million
- Source: Franzini et al.

Ethical Principles

- Respect for autonomy
 - Honoring adolescent's privacy choices
- Non-maleficence
 - Avoiding harm from disclosure
- Beneficence
 - Promoting candor & good clinical care
- Justice
 - Supporting access to care

Professional Organization Policies

- Codes of ethics
- Policy & position papers
- Rationale for supporting confidentiality
- Informing adolescents and parents about confidentiality protections and limits to those rights

Professional Organization Policies: Services, Populations, & Settings

- Policies supporting confidential access to specific health services, such as:
 - Preventive health care
 - Testing & treatment for STDs & HIV
 - Contraception, pregnancy-related services, abortion, & other reproductive health services
- Concerns for specific populations of adolescents
- Confidentiality in particular health care settings

The Legal Framework

- Complex patchwork
- State & federal law
- Constitution, statutes, court decisions
- Reproductive rights
- Family roles
 - Status of minor children
 - Rights & responsibilities of parents

Relationship of Consent & Confidentiality

- “Consent & confidentiality”
- Confidentiality & disclosure in consent laws
- Linkage
 - Clinical practice
 - Ethical guidelines
 - Professional policies
 - State & federal laws

History of Minor Consent Laws

- Earliest laws enacted in 1950s
- Expansion in 1960s & 1970s
- Stability in 1980s
- Attempts to limit in 1990s & beyond

Minor Consent Laws in 50 States & DC

- Minor consent laws in all states
- Minor's status
- Services minor is seeking
- Treatment without prior consent

Consent Laws Based on Status

- Emancipated minor - MI
- Married minor - MI
- Minor in the armed services
- Mature minor
- Minor living apart from parents
- High school graduate
- Minor over a certain age
- Pregnant minor - MI
- Incarcerated minor - MI

Consent Laws Based on Services

- “Pregnancy related care” – MI
- Contraceptive services - MI
- STD/VD (**prevention**), diagnosis, & treatment - MI
- Reportable disease (**prevention**), diagnosis, & treatment
- HIV/AIDS testing & treatment - MI
- Drug or alcohol counseling & treatment - MI
- Outpatient mental health services - MI
- Diagnosis (& treatment) for sexual assault - MI

Consent for Vaccination

- Parental consent when parent is present
- Consent without a parent present
 - Prior written consent, phone, email, text
 - Minor consent
 - with/without parent knowledge
 - based on status
 - based on service
- Vaccine Information Statements (VIS)

Confidentiality Laws

- State Laws
- Federal Laws
- Intertwined, especially through HIPAA Privacy Rule
- Relationship between HIPAA & FERPA

State Confidentiality Laws

- State constitutional right of privacy
- Minor consent
- Medical confidentiality & medical records
- Patient access to health records
- Professional licensing
- Evidentiary privileges
- State funding programs
- Education records

Federal Confidentiality Laws

- Federal constitutional right of privacy
- Federal funding programs
 - Title X
 - Medicaid
- Regulations for federal drug & alcohol programs
- HIPAA Privacy Rule
- Importance of state laws in application of federal laws

HIPAA Privacy Rule: Disclosure

- Disclosure without authorization
 - Treatment
 - Payment
 - Health care operations
 - Other exceptions (e.g. child abuse reporting)
- Disclosure with authorization
 - To anyone else
 - Authorization of parent?
 - Authorization of minor?

HIPAA Privacy Rule: Minors

- Parents are authorized representative of minor child unless minor is considered “individual”
- Minors are treated as “individuals” under HIPAA Privacy Rule in 3 circumstances:
 - Minor has the right to consent and has consented; or
 - Minor may obtain care without parental consent and the minor, a court, or someone else has consented; or
 - Parents accede to confidentiality agreement between minor and health care provider

HIPAA Privacy Rule: Minors as Individuals

- Minor acting as “the individual” can exercise rights re “protected health information”
- Right of the individual
 - Access to information
 - Control over disclosure
 - Request privacy protection

HIPAA Privacy Rule: Disclosure to Parents

- If state or other law requires it, provider must disclose
- If state or other law prohibits it, provider may not disclose
- If state or other law permits it, provider has discretion to disclose
- If state or other law is silent or unclear, provider has discretion to grant or withhold access

HIPAA Privacy Rule: Information Affected

- “Protected health information”
 - Health information
 - Individually identifiable
 - Created or received by a covered entity
- Most SBHCs are covered entities
- “Education records” covered by FERPA
 - **Excluded** from definition of “protected health information” in the HIPAA Privacy Rule

FERPA: Purpose

- Federal Family Educational Rights and Privacy Act
 - Protect the privacy of educational records
 - Assure parental access to records

FERPA: What does it protect?

- “Education Records”
- Records, files, other documents, which:
 - Contain information directly related to a student; and
 - Are maintained by an educational agency or institution or by a person acting for such agency or institution
- Education records include:
 - Records maintained by a school nurse
 - IEP and other special education records maintained by the school
 - Immunization records in school file

FERPA: Access Rules

- Who has access to education records?
 - With rare exceptions, parents must be allowed to review and inspect records on parent request
 - Access to records by anyone other than a parent is restricted, absent parental consent, except in a few circumstances

FERPA: Exceptions to Access Rules

- Education records may be released without parental consent:
 - To other school employees ...
 - “Directory information”
 - Health or safety emergency
 - Child abuse reporting

SBHC Records: HIPAA or FERPA?

- SBHCs/sponsoring agencies
 - Usually “covered entities” under HIPAA
 - If SBHCs are “covered entities” they must follow the HIPAA Privacy Rule with respect to students’ “protected health information”
- Education records are excluded from definition of “protected health information” in the HIPAA Privacy Rule
 - If SBHC records fall within the definition of “education records” under FERPA
 - SBHC must follow FERPA rather than HIPAA access and disclosure rules.

Are records of SBHC subject to FERPA?

- **Joint Guidance** from federal Department of Health and Human Services and federal Department of Education
 - Whether the records of a SBHC are subject to HIPAA or FERPA depends on the relationship between the school-based provider and the educational agency
 - Case by case assessment
 - Relevant factors include:
 - Funding
 - Operational and administrative control
 - Services and functions provided

HIPAA and FERPA

- Similarities:
 - Generally restrict access to records
 - Require written authorization/consent for release
 - Some exceptions that allow disclosure without need of written authorization/consent
- Differences:
 - Parent access rules
 - Who must sign an authorization/consent for release
 - Opportunities for information exchange exist under both laws; however who may exchange information with whom, without a written authorization, is different

Confidentiality Protections: State Minor Consent Laws

- Explicit protection of confidentiality in minor consent laws
- Reference to minor consent laws in other statutes
- Grant of discretion to physician or health care professional to disclose information
 - Disclosure if necessary to protect health of minor
 - No disclosure if minor's health would be harmed

Laws Mandating Disclosure

- Parental notification/consent provisions
- Child abuse reporting statutes
- Disclosure requirements when minor is dangerous to self or others

Recent Efforts to Repeal or Restrict Consent & Confidentiality for Minors

- Parents' rights laws
 - Proposed constitutional amendments
 - Proposed federal & state statutes
- Outright repeal of all minor consent provisions
- Partial repeal of some minor consent provisions
- Limitations of confidentiality
 - Parental notification provisions
 - Parental access to records
 - Direct requirements in federal or state statutes
 - Appropriations riders

Confidentiality Challenges

- Three elephants!
 - HIPAA
 - Billing & insurance claims
 - Electronic health records & web portals

Confidentiality & Commercial Health Insurance

- Widespread use of consumer communications by insurers
- Potential to breach confidentiality & compromise patient privacy
- Intersection of federal & state laws
- Intersection of confidentiality protections & disclosure requirements
 - EOBs & denials of claims

Confidentiality Protections

- Federal law
 - HIPAA Privacy Rule
 - Title X
 - Other federal programs
- State law
 - HIPAA implementation
 - General medical privacy & confidentiality protections
 - Confidentiality for minors

Disclosure Requirements

- Federal law
 - HIPAA Privacy Rule: disclosures for payment
 - ERISA & ACA: notice of denials of claims
- State law
 - Types of communications: EOBs, denials, & others
 - Recipients of communications: policyholder, beneficiary & other
 - Content of communications; provider, type of service, & other
- Commercial insurers policies & practices

Federal DOL, HHS, & Treasury Rules

- “notice of adverse benefit determination”
- Content: date of service, provider, diagnosis code, etc
- “failure to make a payment in whole or in part” includes “any instance where a plan pays less than the total amount of expenses with regard to a claim, including denial of part of the claim due to the terms of a plan or health insurance coverage regarding copayments, deductibles, or other costsharing requirements” [Preamble to regulation]

Confidentiality Protections for Insurance Claims

- HIPAA Privacy Rule
- State laws: significant variation
 - Current law: CA, CO, MD, NY, OR, WA
 - Pending bills: MA, Evolving protections
 - Requests for confidential communications
 - Management of EOBs
 - Restrictions on disclosure
 - Specific protections for adult or minor dependents

HIPAA Privacy Rule: Special Protections

- Request for restrictions on disclosure of protected health information
 - Providers and insurers must allow request
 - Not generally required to comply unless agree
 - Must comply if payment has been made in full by patient or other
- Request for communication by alternate means or at alternate locations
 - Providers must accommodate reasonable requests & may not require statement of endangerment
 - Health plans must accommodate reasonable requests if individual makes statement of endangerment

Management of EOBs

- Requests for confidential communications
 - Incorporation of HIPAA standards
 - Broad definitions of endangerment
- Redirection of EOBs to patient
 - With or without request from patient
- Exclusion of information about sensitive services
- Omission of EOBs when no balance due
- Suppression of EOBs

Restrictions on Disclosure

- Restrictions based on endangerment
 - Statement that disclosure could jeopardize safety of individual
- Restrictions on disclosure of sensitive services
 - Reproductive health, STD, chemical dependency, mental health
 - From whom information should be withheld
 - How payment will be made for cost sharing

Protections for Adult or Minor Dependents

- Adult child or adult dependent covered on a policy
 - Communication between carrier & adult child must remain confidential & private
 - No communication to policyholder without permission of adult dependent
- Restriction on disclosure of sensitive information about services for which minors may consent

EHRs

- Who has access?
 - Adolescent minor patient
 - Young adult patient ≥ 18
 - Parent
- Effect of laws?
 - HIPAA
 - Minor consent laws
 - Insurance laws

Future Policy Implications

- All adolescents should have access to comprehensive health care
- Confidentiality, and the ability to give independent consent, can be important elements of that access
- Absence of confidentiality in billing & insurance may restrict access
- Protecting consent & confidentiality for adolescents is not inconsistent with helping them communicate with parents & other adults
- Current laws provide strong protections but are at risk

Conclusion

- Research findings and current professional & legal guidelines support parental involvement, but also support the availability of confidential adolescent health care for some adolescents & for specific sensitive health problems
- School-based health centers can play important role in providing confidential care for adolescents

Thank You!

Abigail English, JD

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