Non-Adherence

How do you recognize non-adherence?

- Does the minor self-disclose non-adherence?
- Do parents allege non-adherence?
- Is there medical/laboratory evidence of non-adherence?
- Prescription evidence (refill frequency)?
- What are barriers to adherence?
- Are there barriers to adherence or is it "mindfully intentional?"
- Are there resources to help with the barriers? (financial, insurance, housing, legal, transportation, etc.)

Does the patient reside with his/her parents/guardians?

- Are the parents/guardians compromised?
- Are they the barrier to adherence?
- Do they understand the situation concerning ARV therapy?
- Is the minor patient being medically neglected by parents?

Educational Rights

Schooling is an important element of "normal life." Every minor is entitled to a free and public education.

- If disability directly affects learning (e.g., cognitive dysfunction or diminution, sensory deficit), patient is entitled to Individualized Educational Plan (IEP) through Individuals with Disabilities Education Act (IDEA).
- If medical condition only indirectly affects minor's educational experience (e.g., fatigue, frequent absences, medication protocol), minor is entitled to reasonable accommodations and services through either Rehabilitation Act or Americans with Disabilities Act (ADA).

- School district must provide reasonable services so minor may benefit from education services. These accommodations and services must be individualized to meet specific needs of the minor.

Confidentiality in school

- Confidentiality of private health information can, and should, be maintained.
- Disclosure to medical caregivers at school must be held in confidence.
- Disclosure to other school staff (e.g., teacher, coaches) should be made only if required for minor's care.
- No need for general disclosure for "safety's sake of others" in light of "universal precautions/basic precautions" that should be practiced at school.

Common Legal Issues & Concerns of Adolescents with HIV:

A Guide for Clinicians

Confidentiality/Disclosure Education Non-adherence

Warning: The laws pertaining to minors vary tremendously from state to state. Become familiar with the applicable laws.

In most states, a **"minor"** is a person under 18 years of age. Minors are generally without **legal capacity** to make decisions regarding their own medical care unless certain conditions are met.

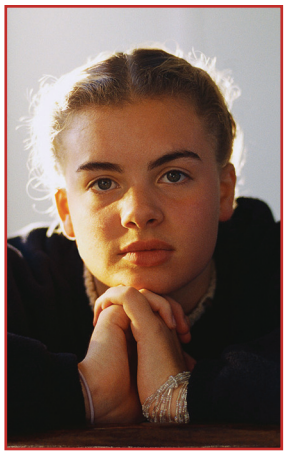
www.aidsetc.org

AETC
AIDS EDUCATION & TRAINING CENTERS

June 2009

Confidentiality of Testing and Treatment

If patient <18 years old, conditions that might provide for legal capacity are:



- Patient legally emancipated. (In some states, this requires a prior and formal judicial decree).
- Patient is a parent of a child.
- Patient being tested or treated for a sexually transmitted infection (STI). (In some states, HIV is not considered an STI).
- Patient being treated for substance abuse.
- Is patient >12 years? (In many states, patients >12 but <18 years, have legal capacity for some interventions).

Is there a specific law pertaining to HIV testing of minors?

- Does it have a minimum age?
- Does it provide for mandatory or discretionary disclosure to parents?
- Does it also address confidential treatment of minors without parental/guardian knowledge?

It's the Law

Mandatory Reporting Laws

- Are there mandatory reporting laws regarding the minor's history (e.g., statutory rape/sexual assault, abuse, neglect, etc.)?
- Boundaries of confidentiality and possible mandatory reporting should be discussed with the patient.
- Regardless of age and other factors, make an "informal" clinical assessment of whether the patient is "mentally competent." Is the patient able to understand the situation and possible outcomes?
- When in doubt, seek consultation: social services, legal department, clinical ethicists.

Accidental Disclosure Concerns

- How will services be paid?
- Where will mail be sent? (E.O.B./Insurance mail)
- How will telephone communication be arranged?
- Is the patient living with his/her parents?
- Why does patient not want the parents to be informed? (May lead to mandatory reporting issues)
- Is the child dependent (i.e., without adequate adult supervision, nurturance, guidance)? (May require social service intervention)

This tool was developed by the Legal Rights & Entitlements subset (Chair: David Korman, JD, PA/MA AETC) of the AIDS Education and Training Centers (AETC) National Resource Center, Adolescent HIV/AIDS Workgroup (Chair: Marion Donohoe, RN, MSN, CPNP, St. Jude Children's Research Hospital, ANAC and Ronald Wilcox, MD, FAAP, Delta Region AETC). Collaborating members include Vera Holmes, LCSW (FXB Center) and Cathy Samples, MD, MPH (NE AETC). The workgroup efforts were coordinated by the AETC National Resource Center (Managing Editor: Megan Vanneman, MPH).

Testing & Treatment

1. A table of state laws pertaining to testing and treatment of HIV of minors: *http://www.guttmacher.org/statecenter/spibs/spib_MASS.pdf*
2. A comprehensive review and copy of each applicable state's laws pertaining to HIV testing by the National HIV/AIDS Clinicians Consultation Center: *http://www.ucsf.edu/hivcntr/PDFs/State_HIV_Testing_Laws.pdf*

Look up your state laws and fill them in below.

Specific HIV consent law(s) for testing and/or treatment?

Minimum age to consent?

Special conditions for consent?

Mandatory/discretionary reporting?

To whom?

Legal assistance:

Social service assistance:

Ethics consultation:

Adolescent Medicine contact:

Education Law assistance:

It is important for the clinician to document carefully:

- minor's situation and concerns.
- options that the clinician considered in addressing those concerns.
- rationale for the option(s) chosen.

Common Legal Issues & Concerns...