

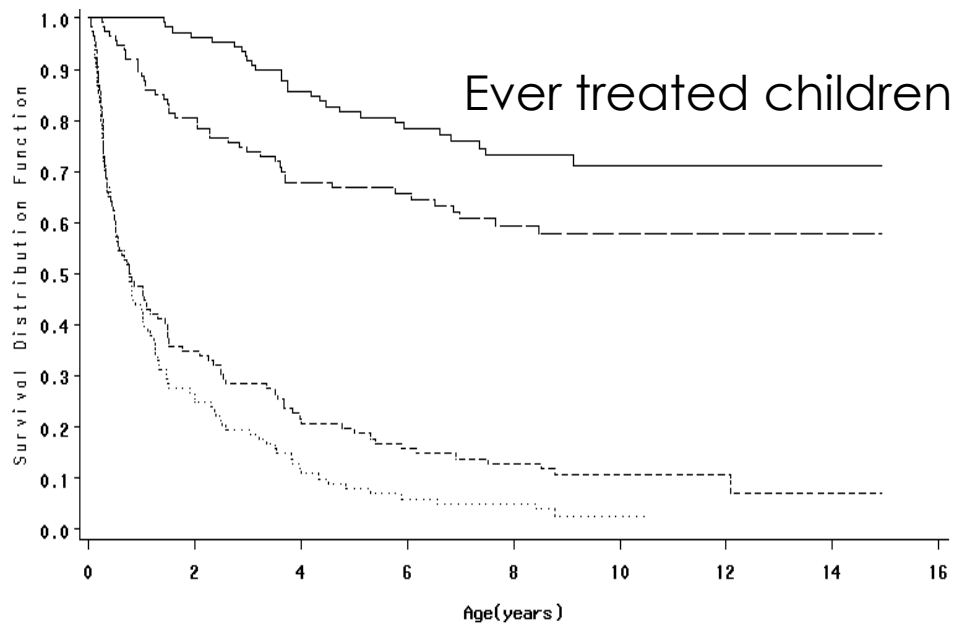
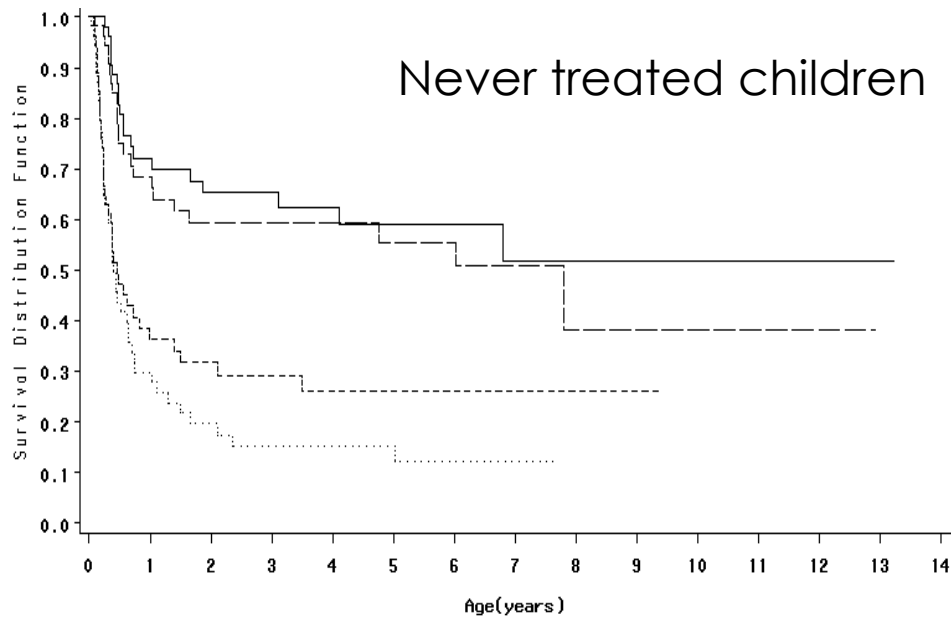
# Adolescents. Management of HIV Infected Adolescents as They Get Into an Adult Outpatient Clinic

Clàudia Fortuny Guasch/Antoni  
Noguera Julian  
Unitat d'Infeccions. Hospital Sant Joan de  
Déu. UB

# HIV infected adolescents



- Vertically-HIV-infected adolescents:
  - Most patients are symptomatic:
    - Direct HIV-related cytopathic effect
    - Secondary to immune suppression
    - Up to 30-40% of patients with an AIDS diagnosis
    - HIV encephalopathy... but also mild delays in specific neurocognitive areas
  - Delayed puberal development
    - Body fat redistribution associated with ART use
- Non-progressors are only 2,4%
- Mild symptomatic patients: 6-15%



## Progression

Cumulative % progressing to C or death:

Untreated: age 1 year: 30%

5 yrs: 43%

10 yrs: 61%

Treated: age 1 year: 12%

5 yrs : 33%

10 yrs: 43%

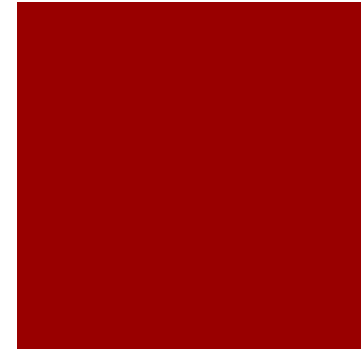
Estimated progression was faster in untreated than treated children: many of the former were enrolled earlier and died before having the chance to be treated.

# HIV infected adolescents



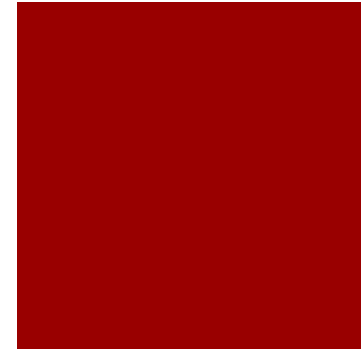
- “Survivors”, and often live with other infected persons
- Many of them are orphans living with:
  - Grandparents or extended family
  - Adopted
  - Foster care

# HIV infected adolescents



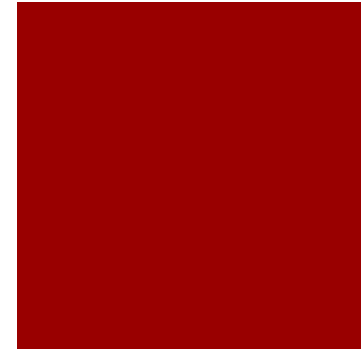
- HIV infection diagnosis should be early disclosed (by the age of 12)
- Gynecological follow-up for girls
- Emotional support
- Counseling on adherence
- Counseling on alcohol, tobacco, cannabis and other drugs
- The transfer to adult care has to be prepared

# HIV infected adolescents



- Regular medical checkups plus...
  - Dentist
  - Nutritionist
  - Dermatologist
  - Psychologist/psychiatrist
  - Social worker
- Academic attainments and professional opportunities
- Peer meetings (with other HIV-infected adolescents)

# HIV infected adolescents



- Increasing difficulties with HAART at this age:
  - Changes in PK/PD characteristics
  - Adherence difficulties (meals, weekends...): **main cause of HAART failure**
  - Advanced disease
  - Resistance-associated mutations accumulation → low number of ART drugs available
  - Interactions with other drugs
- Always choose the “easiest” regimen
- Inform the patient about the drugs, involve him/her the treatment choice and get his/her commitment

# Why is HIV Disclosure Important?



- May increase a child's willingness to adhere to treatment regimen
- Helps children understand the illness
- Avoids an accidental disclosure from occurring (e.g., child overhears caregiver discussing it)
- May decrease behavior problems by decreasing stress
- May improve social functioning and school performance by decreasing stress



# Timing of Disclosure



Will depend on:

- Caregiver's acknowledgment of disease and readiness to disclose
- Child's cognitive skills and emotional maturity (including ability to maintain confidentiality)

Disclosure process should not be rushed, but timing of disclosure becomes more pressing as child nears adolescence.

# Strategies to Facilitate Caregiver Readiness to Disclose HIV Diagnosis to Their Children

<b>Caregiver Fear</b>	<b>Strategy to Overcome</b>
Child is too young or emotionally immature to understand disclosure issues	Partial disclosure: Tell child that medications help keep him/her as healthy as possible. Then, as part of disclosure plan, more information is given, little by little, as the child matures. Introduce the idea of an immune system, or a part of the body that fights infections.

Caregiver Fear	Strategy to Overcome
<p>Child will not understand when not to disclose</p>	<ul style="list-style-type: none"> <li>• Assess child's cognitive and emotional ability to understand and maintain confidentiality and discuss assessment with caregiver</li> <li>• Offer to create a "contract" that outlines who the child can tell and who the child cannot tell.</li> </ul>
<p>Child's reaction will be very difficult</p>	<ul style="list-style-type: none"> <li>• Assure the caregiver that the team will provide support for the family and child before, during, and after disclosure, including mental health assessment and treatment if necessary.</li> </ul>

Caregiver Fear	Strategy to Overcome
<p>Biological parent feels guilty for transmitting HIV infection</p>	<ul style="list-style-type: none"> <li>• Counsel to help alleviate guilt</li> <li>• Engage parent in an affirming and helpful role with child to promote empowerment</li> <li>• Refer for mental health treatment if necessary.</li> </ul>
<p>Caregiver is worried about questions that child may ask about caregiver's sexual behaviors or drug use</p>	<ul style="list-style-type: none"> <li>• Use role playing to prepare caregivers to answer embarrassing or painful questions</li> <li>• Help caregiver decide how to answer questions that may be asked</li> </ul>

<b>Reason for Reluctance</b>	<b>Strategy to Overcome</b>
Caregivers disagree about disclosing to child	Assess each person's concerns and work together to develop a plan. Provide mental health/social work support if necessary
Foster parent and foster agency disagree about disclosure	Arrange for discussion among foster parents, foster agency, and clinical team

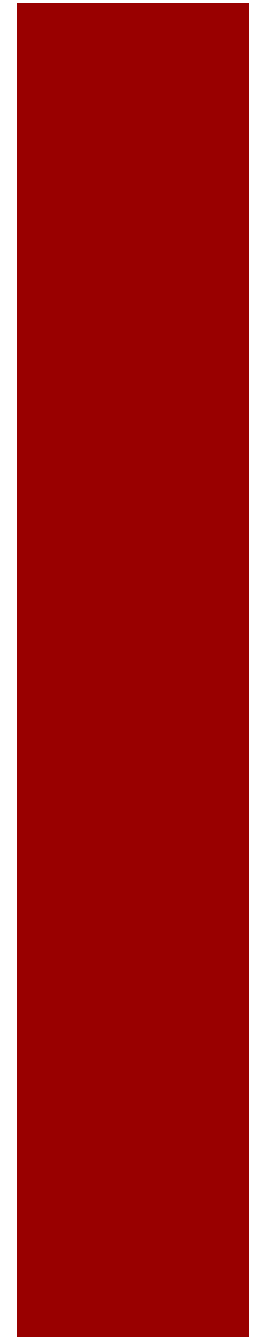
# Factors to consider when developing an individualized disclosure Plan

- **Lying is NOT an option**
- Child's age, cognitive ability, and developmental understanding of illness and mortality
- What child has already been told and what child already knows about medications or doctor visits
- Clinical status of child
- Other disclosures that may need to be made (e.g., adoptive status, paternity issues, or parental HIV diagnosis)

# Factors to consider when developing an individualized disclosure Plan

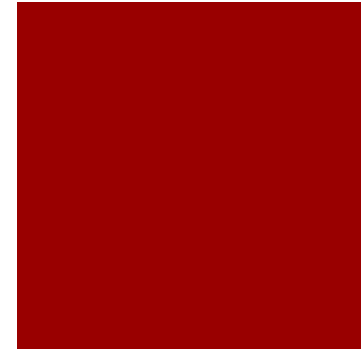
- Caregivers' thoughts about disclosure
- Cultural influences
- Family/social circumstances
- Anticipated response of child when learning diagnosis
- Effect on HIV-infected and non-infected siblings
- Types of support available to the child and family once disclosure occurs (e.g., counseling, peer support groups)

Preparing the  
HIV-infected  
adolescent for  
the transfer to  
adult care



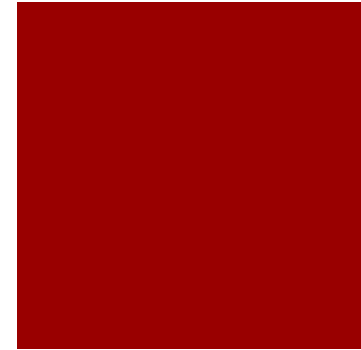


# Hallmarks of Adolescent Development



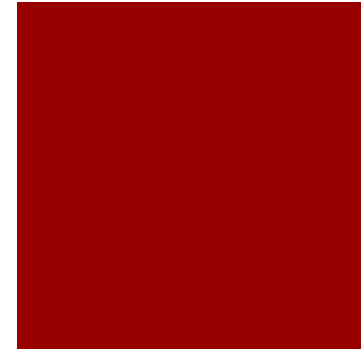
- Sense of immortality
- Risk taking is the norm
- Emerging sense of identity, autonomy and independence
- Challenging authority figures
- Experimentation with sex and gradual development of sexual identity
- Experimentation with substance use
- Peer pressure, positive peer relationships
- Focus on body image

# Adolescence is a time of transition



- Changes in context that may increase risk:
  - Leaving school
  - Leaving home
  - Entering first serious relationship (increase in sexual contact/frequency/partners)
  - First pregnancy
- Context of adolescent sex that may affect risk:
  - Episodic sex that is less likely to be protected
  - Limited access to prevention and knowledge– lack experience/self-confidence/skills

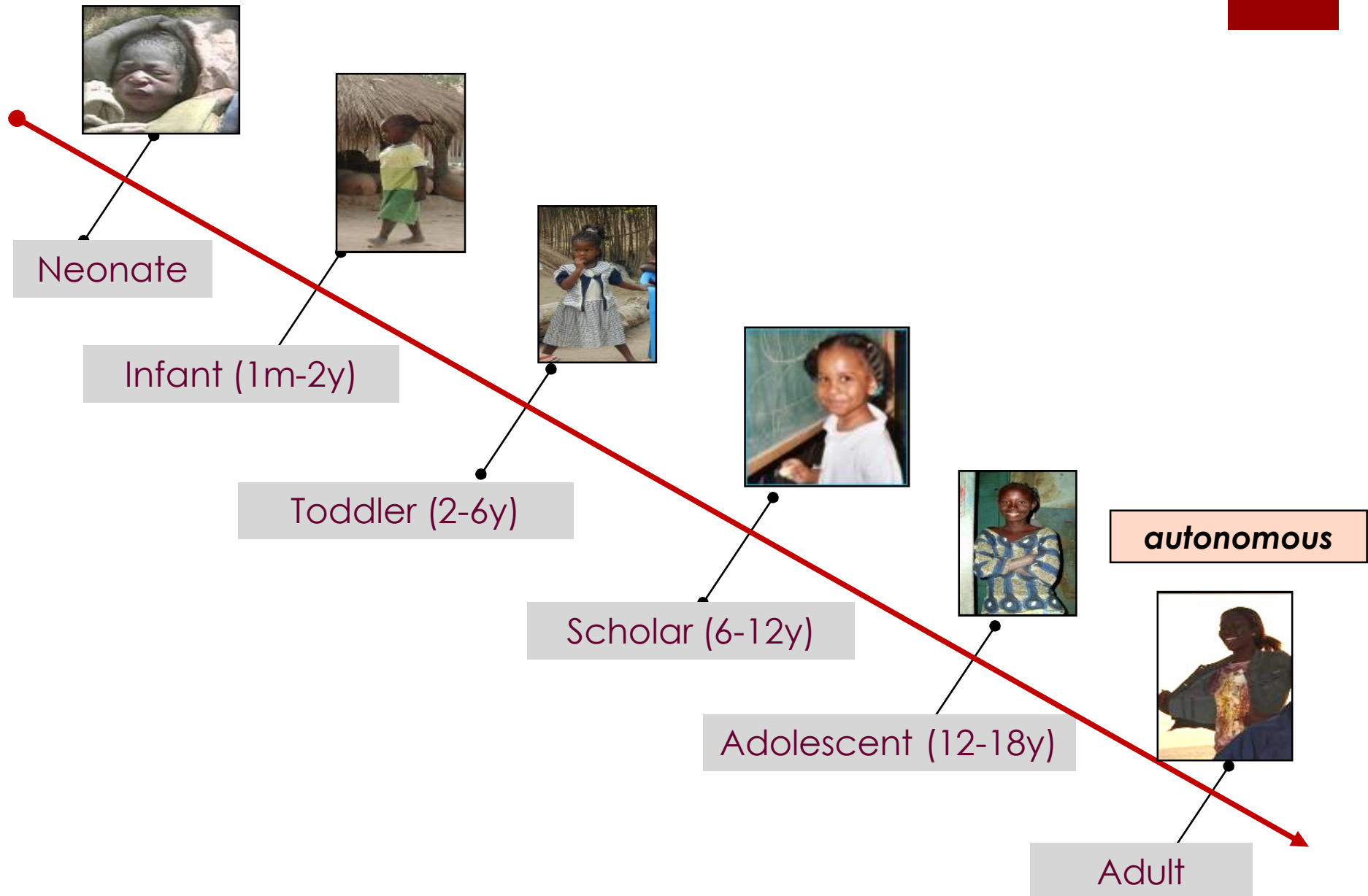
# Mental Health and Psychosocial Issues



- With chronic illness, transition to young adulthood is characterized by psychological distress.
- Many teens with HIV deal with
  - Deaths of parent (s), siblings, friends
  - Lack of family support, community, teachers, schools, society
  - Anger/fear/depression about diagnosis
  - Poverty, substance abuse, violence, trauma, abuse, neglect

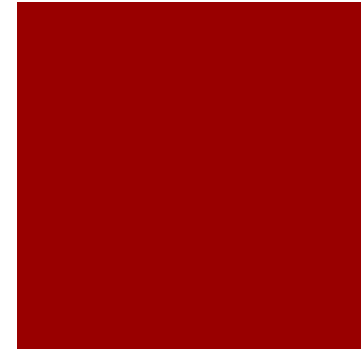
**dependent**

Somatic, emotional and social evolution



# Teen Perspective

## Autonomy and Independence



- *“Why do you have to tell my mom everything?”*
- *“No one trusts me!”*
- *“I’m not taking another pill until you tell me what’s wrong with me!”*
- *“Why didn’t anyone tell me my diagnosis sooner? Didn’t anyone think I can handle it?”*

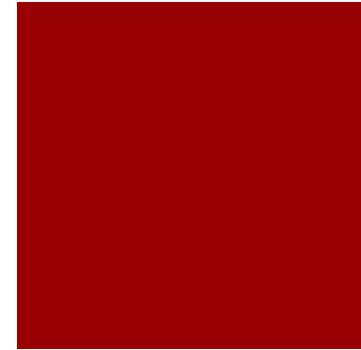
# Provider and Family Perspective

## Autonomy and Independence

- Nurturing versus pampering
- Balancing between giving teen autonomy and risking his/her getting sick
- Fearing loss or limitations in control, lack of power
- Using another provider for “the sex talk” in long-term provider-child relationships

# Interventions

## Autonomy Versus Dependence



- Help developing life skills
  - Daily living and basic needs
  - School and work
- Self-care skills
  - Healthy living and managing HIV
  - Medication Management and Adherence
- Counseling parents about power struggles

# Interventions

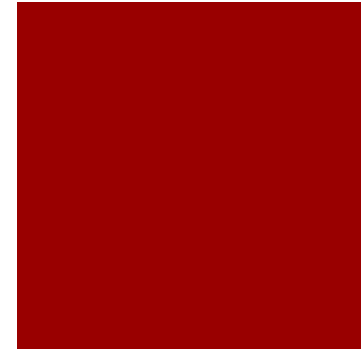
## Managing Their Own Care



- **Information:** What do they know and need to know?
- Adherence to treatment and care
  - Where is the teen in continuum of managing medications?
  - Teen's health beliefs and attitudes
  - Evaluate behavioral, environmental and emotional factors influencing adherence
- Empowering the teen
  - What are your expectations?
  - Taking charge of their healthcare
  - Change their sense of entitlement—"You have to **earn** this"
  - Consider short-term vs. long-term care plan



# Body Image



- Adolescence is a time to define oneself; body image is in the forefront.

“Am I developing normally?”

“Do I look OK?”

“Am I sexually attractive?”

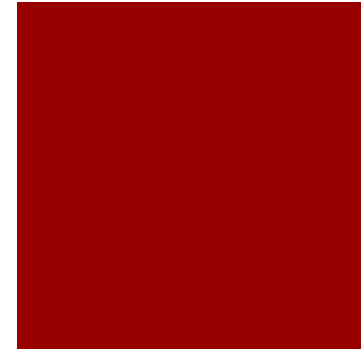
# HIV and Body Image



- Growth and development
- Lipodystrophy
- Wasting
- Obesity
- Skin conditions
- Medical appliances (*i.e.* gastrostomy)

# Interventions & Strategies

## Body Image



- Address growth or pubertal delays
- Consider a proposed treatment's effect on body image and lifestyle
- Involve teen in decisions
- Be willing to change treatment plan

# Peer Relationships

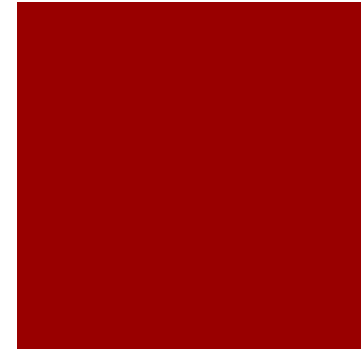


- The focus of adolescent relationships shifts from family to peers, and the peer group sets behavior standards.

“Yeah I have a tattoo—  
all my girlfriends have one.”

- Fearing rejection, disclosure to peers is rare— only to a best friend after “testing” relationship, e.g.,  
*“How do you feel about people with AIDS?”*

# School



- May be behind in grade, have cognitive delays or special learning needs
- Absenteeism may be an issue
- Disclosure to the school is rare
- Education and/or vocational training are important in the long-term

# Youth Sexual Behaviors

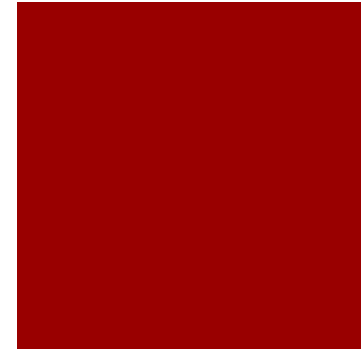
## General Population



- 46% ever had sexual intercourse
- 14% ever had four or more sex partners
- 42% did not use a condom during last sexual intercourse
- 82% did not use birth control pills during last sexual intercourse
- 89% had received HIV/AIDS education

# Teen Perspective

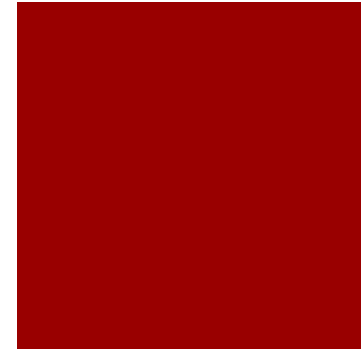
## Sexuality



- Anxiety regarding
  - Sexuality
  - Sexual relationships
  - Reproductive and sexual functions
- *“I have the same doctor since I was a baby; he’s like my parent. I can’t talk to him about sex. I don’t want to disappoint him.”*
- *“I’m going to yes them to death because I can’t tell them the truth.”*

# Provider Responsibility

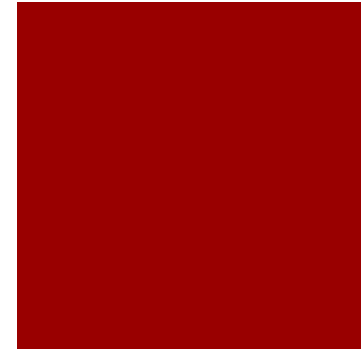
## Anticipatory Guidance



- Discuss sexual anatomy and function, and contraception
- Teach basics regarding transmission; discuss safe and responsible sex
- Encourage caregivers to recognize need for teen sexual identity
- Have videos, pamphlets, youth magazines in the clinic/office



# Reproductive Health/ Family Planning



- Many adolescents, HIV-infected or uninfected, want to have children
- Can be a strong desire; they have personal sense of mortality

“I want to leave some part of me on the earth”

- Assure teens that they **can** have children safely when the time is right

# HIV and Plans for the Future

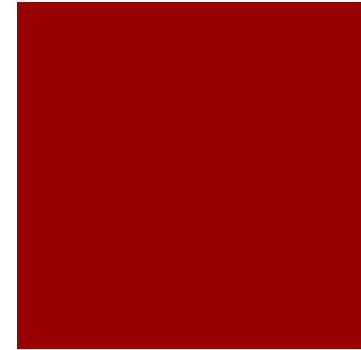


- Planning for the future is hard for teens
  - They were not expected to survive into adulthood
  - Their future *remains* uncertain
  - Many experience depression, loss, hopelessness and despair
- Career Planning Support
  - To develop skills for job and independence
  - Key—stay well to be part of the future

“I’m older now— I actually have to do something with my life.”

# Interventions

## School to Work

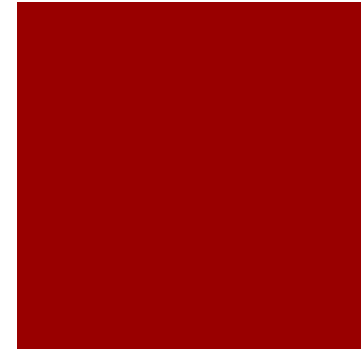


- Start early—build expectations
- Identify passion and skills for future job
- Encourage education as much as possible
- Find mentors
- Teach or refer for life skills
- Assist teen in taking care of their own entitlements

Transfer to adult  
care



# Principles of Healthcare Transition



- Begin healthcare transition early
- Continuity of care is the goal
- Transition planning should be comprehensive
- Involve teen and family
- Service coordination, communication and collaboration between providers is essential

# Interventions & Strategies

## Transition



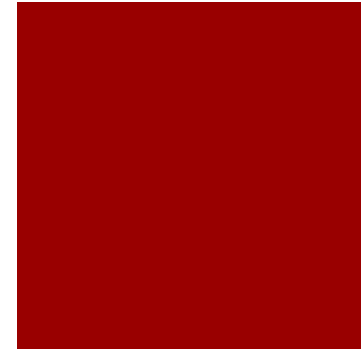
- Maintain a relationship with teen and family
- Stimulate discussion about teen's future
- Understand the nature and implications of teen's chronic illness
- Determine time for transition discussions based on teen's development and needs
- Practice family-centered care
- Include support groups, mental health consultation and family planning component

# Challenges to successful transitioning



- Adolescents and/or family and/or care team resistant to change.
- Radical differences in expectations and clinic cultures between pediatric/adult care settings.
- Communication difficulties between providers.
- Inadequate time and resources in adult medicine practice settings.

# Challenges to successful transitioning



- Stigma of being infected with HIV and, for many-HIV youth, the additional stigma being gay, transgender, a substance user, or a teenage mother.
- High rates of teen pregnancy
- Non-disclosure to partners or roommates.
- Non disclosure by parent or guardian
- Recognize different needs of perinatally infected vs behaviorally infected youth



# Transition Resources



## Practitioner Transition Checklist & Timeline

Healthcare	Age 14-16	Age 17-19	Age 20-24
Meet privately with youth for part of visit	✓ ✓	✓ ✓	✓ ✓
Encourage youth to assume increasing responsibility of own health care	✓ ✓	✓ ✓	✓ ✓
Education			
Focus on youth's course of study as it relates to their long-term plans and goals	✓ ✓	✓ ✓	✓ ✓
Employment			
Initiate discussion of different routes to employment, e.g. higher ed or technical training	✓ ✓	✓ ✓	✓ ✓

# Youth-friendly HIV care



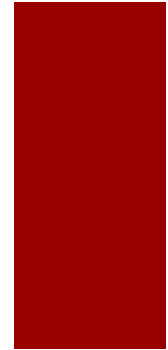
- Providers who are knowledgeable, nonjudgmental
- Confidentiality and Consent
- Socioeconomic: poverty, work, school, housing & transportation challenges
- Empowering youth to LIVE with HIV
- Integrated care/"one stop shop"

# Prevention with Positives



- Key element of HIV care and public health
  - Importance of age-appropriate messaging
- Prevention messages
  - Protect yourself/others from STIs and new HIV
  - Condomize every time you have sex
  - Engage partners: testing/disclosure if safe
  - Fewer partners = less risk
  - Drugs and alcohol = greater risk (SEP)
  - Consider not having sex (other ways to express love)
  - Discuss safe pregnancy options (PMTCT)

# Summary: successful transitioning



## Paediatric-adolescent team:

- Diagnostic disclosure
- Follow-up:
  - Clinical/immune
  - HAART / adherence
  - Prevention
- Transfer to adult care to begin early
- Future planning
- Coordination with adult team

## Adult team:

- Know special characteristics of perinatally infected youth
- Adapt daily practice to those characteristics:

# A propos of a case # 1

Joana is a 16-year-old HIV-infected girl on Atripla. She is coming with her boyfriend, who knows nothing about her HIV infection, because of 8-wk amenorrhea.

- Pregnancy test is positive
- Ultrasound confirms gestation

## **What to do?**

- Regarding gestation
- Disclosure of gestation to her parents
- Disclosure of HIV to her boyfriend

## A propos of a case #2



- Pere is a 14-year-old perinatally-HIV-infected boy. He is currently doing well, with normal CD4 counts, but 2 last viral loads have showed blips despite of HAART: viral failure.

### **Why is he failing?**

- Low adherence; he knows he is infected but ignores HIV.
- Low adherence; change in daily habits.
- Low adherence; drug user?

## A propos of a case #3

- A previously healthy 17-year-old boy is coming with his mother because of a rash. He wants her mother to leave the room and admits having had risky homosexual relationships. He wants us to test him for HIV.
- HIV and syphilis test positive
- **What to do regarding disclosure to parents**



# References:

- <http://www.cdc.gov/topics/surveillance/resources/slides/adolescents.indez.htm>
- <http://www.medscape.com/viewarticle/7748356>
- <http://www.AdolescentAIDS.org>
- <http://www.hivcareforyouth.org>



Moltes gràcies

[cfortuny@hsjdbcn.org](mailto:cfortuny@hsjdbcn.org)

[ton@hsjdbcn.org](mailto:ton@hsjdbcn.org)

