

# Transitional Care for HIV and AIDS from Adolescence to Adulthood

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# Disclosure Statement

- Richard Weinstein and Phyllis Jones
- Has no financial interest or relationships to disclose.
- HRSA Education Committee Disclosures  
HRSA Education Committee staff have no financial interest or relationships to disclose.
- CME Staff Disclosures  
Professional Education Services Group staff have no financial interest or relationships to disclose.

# Learning Objectives

1. By the end of the session, participants will be able to have a working understanding of developmentally appropriate assessment tools to guiding a youth through the transitioning process.
2. By the end of the session, participants will be have an understanding of how to integrate transitioning services into their existing program models with either existing staff or developing a new staff position to achieve a functioning transitioning program. This will include being able to track long term outcomes for patients who have transitioned into adult care.
3. By the end of the session, participants will have a working knowledge of the barriers and obstacles both youth and providers face when dealing with transitioning into adult care. Strategies to overcome these obstacles will be discussed for participants.

# Overview/Background Concepts

- Age group: 18-24 years
- Definition of “transition”
- Developmental Concepts
- Two distinct/overlapping subgroups:-
  - Perinatally infected with HIV; first generation of long term survivors
  - Behaviorally infected with HIV
- Unique clinical issues within each group
- Different Models of Care
- Case Studies
- Outcomes in transition

“Transition is a multifaceted, active process that attends to the medical, psychosocial, and educational or vocational needs of adolescents as they move from the child-focused to the adult-focused health-care system. Health care transition facilitates transition in other areas of life as well (eg. work, community, and school).”

-Reiss, J, Gibson R. Health Care Transition: Destinations Unknown.

*Pediatrics. 2002;110:1307-1314*

“Most developmental transitions create anxiety... timing of the transition will depend on developmental readiness, complexity of the health problems, characteristics of the adolescent and family, and the availability of skilled adult health providers.

Transition is more complex and generally more difficult for those with more severe functional limitations or more complicated medical conditions.”

- Reiss, J, Gibson R. Health Care Transition: Destinations Unknown.

*Pediatrics. 2002;110:1307-1314*

# Increasing Average Age of Survival for Childhood Chronic Diseases

Cystic Fibrosis	
1973	7 years
2002	21 years or greater
Spina Bifida	
1970s	<33% reached 20 years
2002	>80% reached 20 years
Sickle Cell Disease/Renal Disease	
N/A	N/A

Reiss, J, Gibson R. Health Care Transition: Destinations Unknown.  
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# Hallmarks of Adolescent Development

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





# Hallmarks of Adult Development

- Independence:
  - Self-reliant, independency, move from family home to independent living
- Establishing personal identity:
  - Sense of who I am as unique individual
  - Critical aspect of achieving sense of independence
- Establishing intimacy:
  - Young adults desire intimate relationships, sharing experiences with another



# Multiple Transitions

- “Where do I fit in?”
  - Doctor, clinic setting, self consent for care
  - Foster care
  - School
  - Camps and youth programs
  - Cumulative loss and bereavement



# Two Epidemiologic Subgroups

Perinatally  
Infected  
with HIV

Behaviorally  
Infected  
with HIV

- These two groups have both distinct as well as shared clinical and psychosocial characteristics

# Timeline

1982

First reports of perinatal transmission of HIV in New York, New Jersey and California

1996

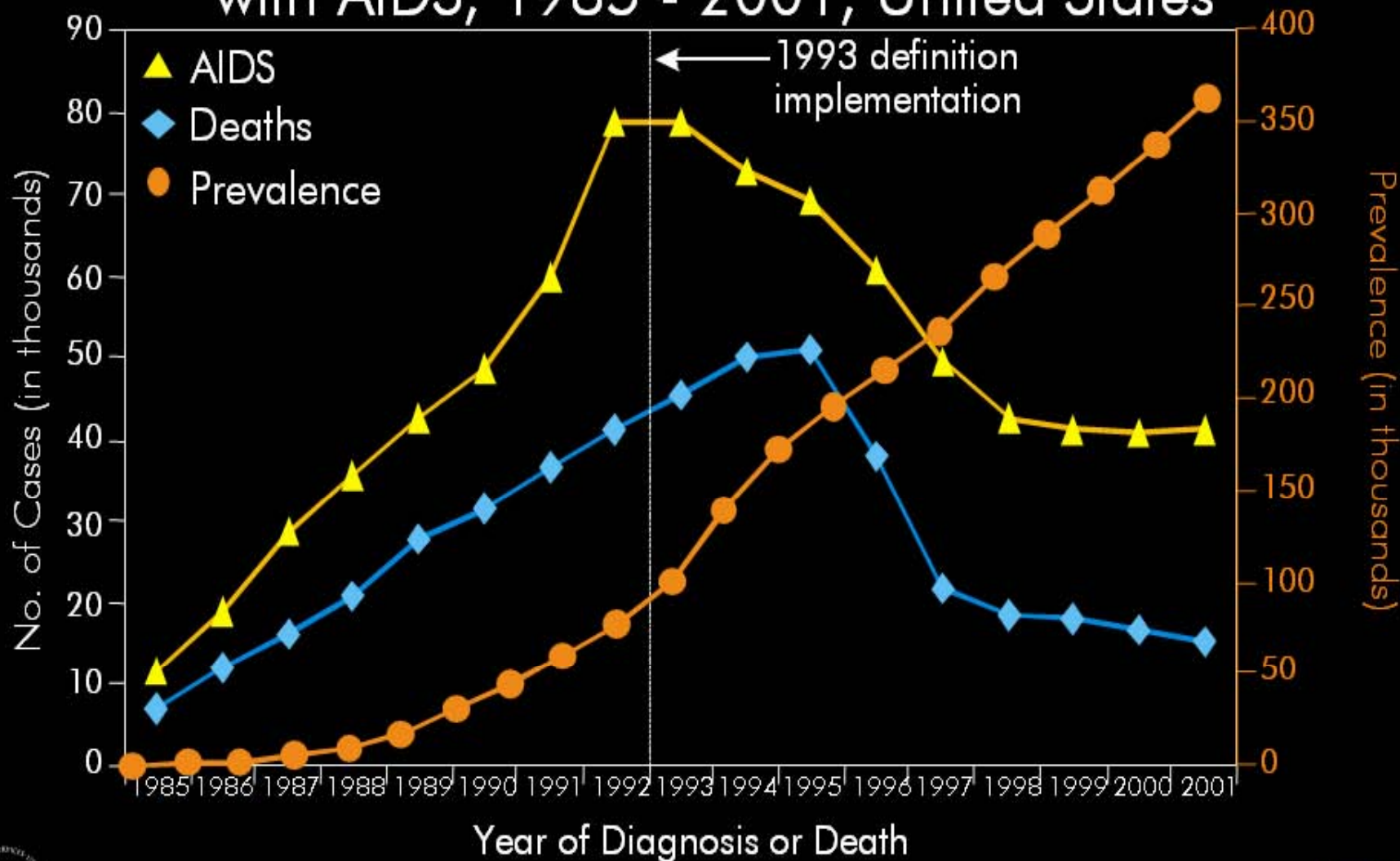
Release of first protease inhibitors leading to trend of increased survival

2004-2020

Approved antiretroviral agents; 5 different classes; several combination pills; regimens with lower pill counts and once a day regimens

(MMWR December 17, 1982/31(49) 665-667)

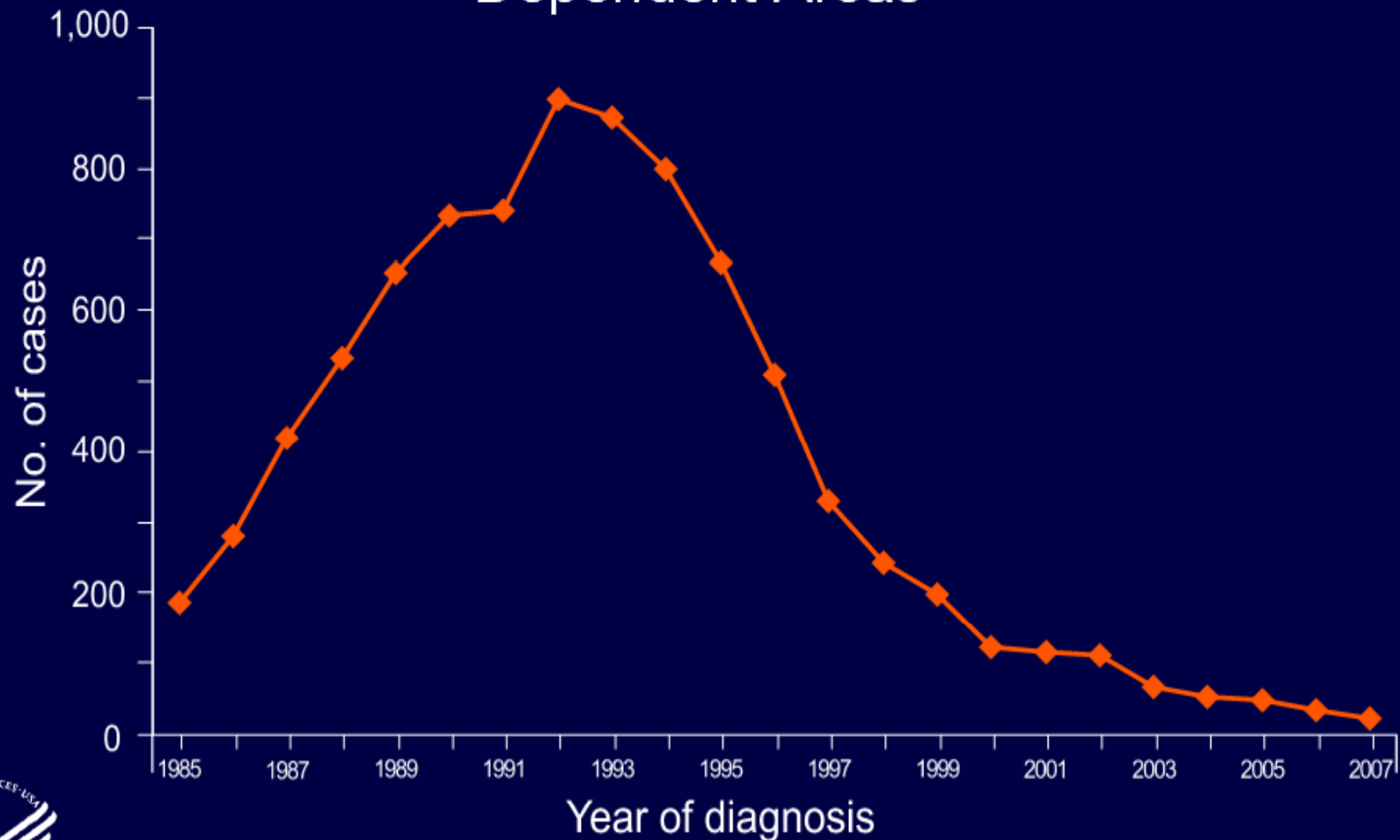
# Incidence, prevalence and deaths among persons with AIDS, 1985 - 2001, United States



Data adjusted for reporting delays and for estimated proportional redistribution of cases reported without a risk; data reported through June 2002



# Estimated Numbers of Perinatally Acquired AIDS Cases by Year of Diagnosis, 1985–2007—United States and Dependent Areas



Note. Data have been adjusted for reporting delays and missing risk-factor information.



# Trends in Long Term Survival from Perinatal HIV Infection

- In 2006, 42% of adolescents who were infected with HIV before the age of 13 comprised were perinatally infected
- This proportion will likely decrease over time, given the reduction in perinatal HIV transmission since the 1990s.
- There are fewer and fewer cases of perinatally infected youth being born today.



# Unique Clinical Issues in Perinatally Infected vs. Behaviorally Infected Youth

- Behavioral:
  - more likely to be in earlier stages of HIV disease
  - less OI complications
  - no previous ARV exposure/ less likely to be resistant to ARV's/less likely to require HAART
  - when HAART required can give simpler regimens
  - treatment adherence problems may be relatively simpler to manage than perinatal group
  - more likely to achieve functional autonomy



# Unique Clinical Issues in Perinatally Infected vs. Behaviorally Infected Youth

## ■ Perinatal: More Likely.....

... to be in more advanced stages of HIV disease and immuno-suppression

... to have hx of OI's with complications/ disabilities (eg. blindness, O2 dependent, chronic renal failure)

... to have heavy ARV exposure hx therefore more likely to have multi-drug resistant virus

...to require HAART to control viremia, low CD4 counts

# Unique Clinical Issues in Perinatally Infected vs. Behaviorally Infected Youth

- Perinatal Outcomes:
  - more complicated ARV regimens (eg. “mega-HAART”)
  - more complicated non-ARV medications such as OI prophylaxis/treatment
  - greater obstacles to achieving functional autonomy due to physical and developmental disabilities/greater dependency on family (eg. “adult” vulnerable child)
  - when pregnant, higher risk of complications during more advanced stages of disease

# Mental Health Profile of Perinatally Infected Adolescents

ADHD	15.9%	(11/69)
Behavior Problems	29%	(20/69)
Psychiatric Dx	17.4%	(12/69)

Perinatally infected adolescents also have a significant prevalence of residua of developmental delay and regression

# Mental Health Profile of Perinatally Infected Adolescents

“....although a high prevalence of behavioral problems does exist among HIV-infected children, neither HIV infection nor prenatal drug exposure is the underlying cause. Rather, other biological and environmental factors are likely contributors toward poor behavioral outcomes.”

Mellins, Smith, et al.  
WITS Study, Pediatrics. 2003 Feb, 111(2):384-93

# Mental Health Profile of Perinatally Infected Adolescents

- Forty-seven perinatally-infected youths 9-16 years of age and their primary caregivers recruited from a pediatric HIV clinic were interviewed using standardized assessments of youth psychiatric disorders and emotional and behavioral functioning, as well as measures of health and caregiver mental health.
- According to either the caregiver or child report, 55% of youths met criteria for a psychiatric disorder. The most prevalent diagnoses were anxiety disorders (40%), attention deficit hyperactivity disorders (21%), conduct disorders (13%), and oppositional defiant disorders (11%).
- Psychiatric disorders in youth with perinatally acquired human immunodeficiency virus infection.

Mellins et al. *Pediatr Infect Dis J.* 2006 May;25(5):432-7

# Mental Health Profile of Behaviorally Infected Adolescents

(self-reported)

Hx of depression (non-HIV related)	55.7%
Hx of suicidal ideation	20%
Hx of suicidal gestures/attempts	30%
Hx of other psychiatric dx	24.3%
Dropped out of JHS, HS or college	32.4%

# Mental Health Profile of Behaviorally Infected Adolescents

(self reported)

## Substance use:

EtOH	23.6%
Marijuana only	3.64%
EtOH/Marijuana	38.2%
Crack/Cocaine	20%
IVDU	1.82%
Other	16.4%

# Differences in HIV Care Models: Pediatric vs. Adolescent vs. Adult

## ■ Pediatric:

- Family-centered and multidisciplinary care with pediatric expertise
- Medical provider has more long standing relationship with care giver at home
- Primary care approach integrated into HIV care
- Issues of HIV disclosure to patient and youth's confidentiality/right to consent
- Care usually offered in discreet, child-friendly and intimate setting
- Teen services supplemental to existing services



# “Supplemental” Clinical Services for Perinatally Infected Youth



Sexuality

Pelvic examinations/  
Pap smears

STD  
screening

Pregnancy

Issues of treatment options

Substance  
use

Treatment adherence

# Youth Rights to Consent and Confidentiality in New York State

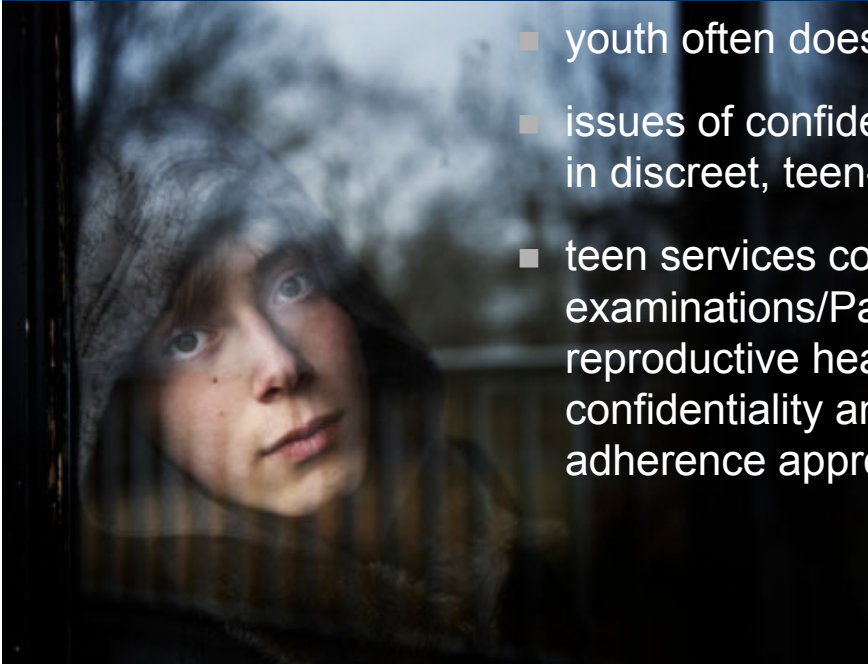
- STD screening and treatment
- Family planning/birth control
- Prenatal care
- Termination of pregnancy
- HIV counseling and testing
- HIV care
- Substance abuse treatment
- Mental health services
- Transgender care



# Differences in HIV Care Models: Pediatric vs. Adolescent vs. Adult

- Adolescent:

- teen-centered and multidisciplinary care; provider may have minimal to no relationship with parent/care giver
- primary care approach integrated into HIV care
- youth often does not disclose HIV status to family
- issues of confidentiality and consent; care usually offered in discreet, teen-friendly and intimate setting
- teen services core to clinic-sexuality, pelvic examinations/Pap smears, STD screening and tx, reproductive health, substance use, rights to confidentiality and consent, treatment education and adherence approaches



Adolescent photo

# Differences in HIV Care Models: Pediatric vs. Adolescent vs. Adult

- Adult:
  - Adult-oriented care based on strict medical model
  - Adult medical providers more often ID specialists than are pediatric or adolescent providers
  - Young person's transitional issues usually not given any systematic specialized focus
  - Clinics tend to be very large and easy for transitioning patients to "slip through the cracks" unless very motivated`

# Life Skills That an Adolescent Needs for Successful Transition to an Adult Clinic

- Knowing when to seek medical care
- Being able to identify and describe symptoms
- Using one's PCP appropriately
- Making, canceling, and rescheduling appointments
- Punctuality
- Calling ahead of time for urgent visits



# Life Skills That an Adolescent Needs for Successful Transition to an Adult Clinic

- Responsible Self Care
  - Requesting prescription refills correctly and allowing enough time for them to be refilled before needed
  - Negotiating multiple providers and subspecialty visits
  - Understanding the importance of healthcare insurance and how to get it
  - Understanding entitlements and knowing where to go for each
  - Establishing new relationship with care providers

# Barriers to Successful Transitioning

- Provider resistance
- Adolescent and/or family resistance
- HIV-specific barriers to transitioning-role of disclosure
  - HIV status
  - stigma

# CASE STUDY

24 year old male, perinatally infected with a major psychiatric disorder- dx with bi-polar and schizoaffective disorder.

- Facilitation of psychological issue.
- Case management needs addressed.
- Future facility care development.



# CASE STUDY

24 year old female, perinatally infected with neurological complications.

- Keeping client medically stable.
- Psychological preparation.
- Case management needs addressed.
- Outside activities engaged.
- Communication with adult clinic.

# What Questions Need to Be Addressed?

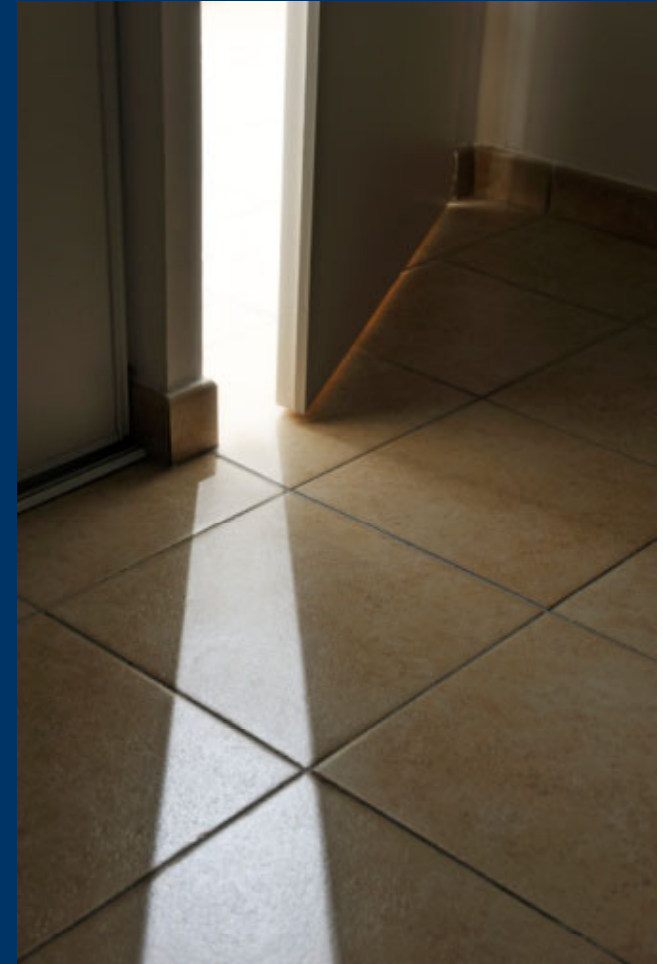
- How do youth who transition access services in adult care?
- Does their experience in the peds/adol setting affect how or whether they access a variety of services in the adult setting?
- How do mental health factors impact transition?

# What Questions Need To Be Addressed?

- What factors are associated with successful transition?
- What early interventions might be associated with a better outcome?
- Does teen pregnancy and motherhood enhance or deter transition?

# What Questions Need To Be Addressed?

- How do you measure life skills?



# Recommendations

- Orient patients and families towards the future emphasizing long term survival
- Develop a transition plan early when it is still many years ahead
- Foster personal and medical independence early; children should assume some responsibility for their treatment at home and at school; adolescents should be permitted and encouraged to participate in decision-making and consent

# Recommendations

- Transition plans should be multifaceted and individualized:
  - Medical: old provider should be familiar with new provider as clinician and the environment in which they provide care
  - Mental health: goal should be to transition psychotherapy/psychiatric services simultaneously with medical services; often a challenge
  - Psychosocial: housing/entitlements, health insurance should all be in place
  - Life skills: educational goals, job training, parenting, etc.

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