Transitioning Children and Adolescents with HIV Infection to Adult Care:

How do we get there? Perspectives and Challenges

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I have no real or perceived financial disclosures to make or conflicts of interest to disclose regarding any commercial products or therapies.

I will not promote the use of any products during this discussion.

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Objectives

- Review health care transition processes.
- Explore particular factors that influence health care transition for children and youth with HIV infection.
- Discuss potential processes for successful transition to adult HIV specialty care.

Background and Significance

- Approximately 13% of US children have special health care needs
- > 90% reach adulthood
- Less likely to:
  - finish high school
  - pursue post-secondary education
  - find a job
  - live independently

US DHHS, 2001

Adolescents are:

- Not children
- Not adults
- Childlike in thought and behavior maybe
- Adult physically perhaps
- Have ongoing brain changes and cognitive maturation

Definition

- **Health care transition is a <u>purposeful, planned process</u> that supports adolescents and young adults with chronic health conditions and disabilities to move from child-centered (pediatric) to adult-oriented health-care practices, providers, programs, and facilities.**
- **It is not merely "transfer" of care.**

Blum et al., 1993 for IOM report

Why Does Effective Transition Matter?

* Number of medical visits declines after transfer to adult care
* Patients self-report lower adherence to treatment after transfer
* Patients cite difficulty in establishing rapport with adult providers
* Lack of appointment reminders interferes
* Perception that adult providers don't "know" them or "value" them

AAP Statement on Transition - 2011

* Health care transition planning starts as early as ~age 12
* Actual transition planning by age 14
* Age 16-17: transition planning well established
* Age 18: initiate adult model of care, even if no transfer of care
* Written transition policy should be displayed
* Each practice should use a standard transition plan
* Review transition plans regularly and update accordingly
* Medical records should be delivered to adult provider, as well as portable health summary to youth/family

Who is an Adolescent?

- American Academy of Pediatrics: 12-21 years old
- Society for Adolescent Health and Medicine: 10-24 years old
- American Psychological Association: 10-18 years old
- American Medical Association: 11-21 years old
- National Institutes of Health: 13-24 years old
- World Health Organization: 10-19 years old

In general: second decade of life,
time between "childhood" and "adulthood."

Importance of Planning

- Young adults with disabilities and special health care needs require ongoing medical care.
- Health care transition doesn't happen automatically.
- Expertise of care amongst adult providers needed.
- Anticipation of need for health insurance.
- Social and legal aspects of independence; integration of medical and social/environmental factors.
- Requires time, practice, and teamwork!

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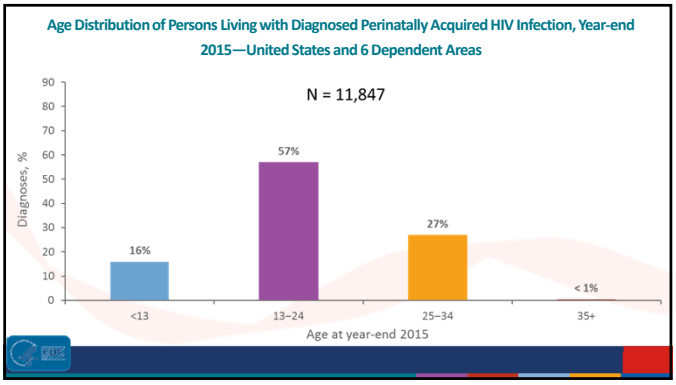
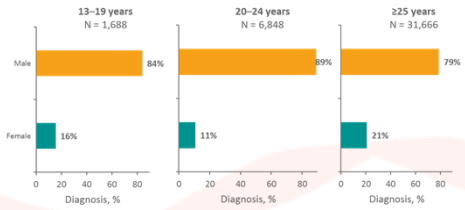


Diagnoses of HIV Infection among Persons Aged 13 Years and Older, by Sex and and Age Group, 2016—United States and 6 Dependent Areas



Note. Data for the year 2015 are preliminary and based on 6 months reporting delay.

Diagnoses of HIV Infection Among Male Adolescents and Young Adults, by Age Group and Transmission Category, 2016—United States and 6 Dependent Areas

	13–19 years		20–24 years	
Transmission category	**No.**	**%**	**No.**	**%**
Male-to-male sexual contact	1,321	92.7	5,595	91.6
Injection drug use (IDU)	15	1.0	88	1.4
Male-to-male sexual contact and IDU	40	2.8	188	3.1
Heterosexual contact[a]	42	3.0	234	3.8
Other[b]	6	0.4	6	0.1
Total[c]	**1,424**	**100**	**6,111**	**100**

Note. Data for the year 2015 are preliminary and based on 6 months reporting delay. Data have been statistically adjusted to account for missing transmission category.
[a] Heterosexual contact with a person known to have, or to be at high risk for, HIV infection.
[b] Includes hemophilia, blood transfusion, perinatal exposure, and risk factor not reported or not identified.
[c] Because column totals for numbers were calculated independently of the values for the subpopulations, the values in each column may not sum to the column total.

Diagnoses of HIV Infection Among Female Adolescents and Young Adults, by Age Group and Transmission Category, 2016—United States and 6 Dependent Areas

	13–19 years		20–24 years	
Transmission category	**No.**	**%**	**No.**	**%**
Injection drug use (IDU)	17	6.5	76	10.4
Heterosexual contact[a]	222	84.2	650	88.2
Other[b]	25	9.4	10	1.4
Total[c]	**264**	**100**	**737**	**100**

Note. Data for the year 2015 are preliminary and based on 6 months reporting delay. Data have been statistically adjusted to account for missing transmission category.
[a] Heterosexual contact with a person known to have, or to be at high risk for, HIV infection.
[b] Includes hemophilia, blood transfusion, perinatal exposure, and risk factor not reported or not identified.
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Transition Challenges for Adolescents with Perinatally-Acquired HIV

- Secrecy vs. public disclosure
- Traumatic losses (parents, siblings, extended family)
- Complications of chronic illness and ARV meds
- Multiple drug resistance
- Problems with adherence (pill fatigue)
- School failure/educational challenges
- Evolving sexual awareness, identity, pregnancy
- Depression, social anxiety
- HIV secondary prevention and legal concerns

Transitioning:

THE YOUTHS' PERSPECTIVES FROM FOCUS GROUP AT U OF MIAMI IN 2015

Where to begin….

- **ASK QUESTIONS!**
  - when does transition begin for me?
  - who will help me with this process?
  - what do I need to know?

Youth and Families: Barriers

- **Not well-informed or prepared about adult service systems:**
  - Fewer available programs
  - Stricter eligibility criteria
  - Increased financial burden
  - Termination of childhood support systems
- **Medical practitioners not proactive in planning for transition**

Youth and Families: Barriers (cont.)

- **Confusion about available resources**
- **Youth not taking responsibility for managing own care**
- **Legal implications when youth reach age of majority**
- **Communication difficulties**
- **Worry about finding a knowledgeable, caring adult provider**

Pediatric Experiences / Practices

Attention to preparing youth:

- Improving communication skills
- Describing own medical condition or special needs
- Taking medication/doing treatments independently
- Knowing legal rights
- Learning about health insurance
- Accessing community resources

Pediatricians: Other Barriers

- **Office staff who:** coddle and won't let go!
- **Parents who:**
  - Are overly emotional
  - Are overprotective
  - Have unrealistic expectations
- **Systemic barriers:**
  - Adequate health insurance after age 18
  - Fragmented and complex adult systems
  - Limited public assistance for adults with disabilities
  - Minimal case management in adult practices

Limitations of Adult Providers: Contributing Factors

- **Managed care guidelines**
- **Low reimbursement rates**
- **Time required**
- **Communication barriers**
- **Lack of resources/supports**
- **Lack of information about existing community agencies/services**

TRANSITIONING YOUTH INTO ADULT CARE

Principles of Transitioning

- Process vs. event
- Could begin at the day of diagnosis
- Providers/Caregivers need reminders to ***let go***
- Adolescent must be involved in the decision-making
- Coordination across the SYSTEMS is essential

TRANSITIONING YOUTH INTO ADULT CARE SUCCESSFUL STRATEGIES

- Pediatric provider recommends adult provider options
- Pediatric provider offers youth medical history
- Mentors/Buddies assist
- Youth become expert in their own health care condition
- Multiple intervention strategies (support groups, newsletters, case manage)
- Providing in-service training for adult healthcare providers
- Nurse or social worker oversees transition process

MODELS OF TRANSITION SERVICES

Disease-specific

- Pediatric specialist to pediatric/adult specialist (Med-Peds?) to adult specialist provider (ID specialty could follow across the spectrum)

Generic

- Patient moves from pediatrics setting (birth-12) to adolescent setting (13-24) to adult (>24 years)

MODELS OF TRANSITION SERVICES

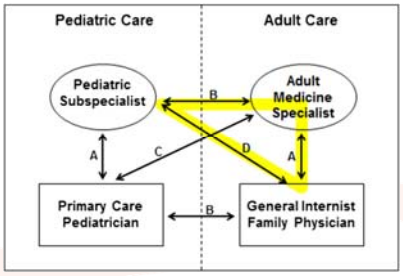
Primary Care

- Primary Care Provider (PCP) is care coordinator
- Specialist is the consultant

Single Site Specialty

- Pediatric to adolescent to adult care within the same environment
- Clinical services remain constant

Structural basis for collaboration and co-management in care transition



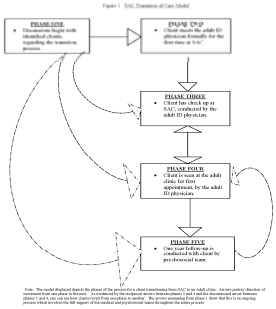
Edward L. Schor Pediatrics 2015;135:958-960

PEDIATRICS

Recommended Strategies

Models of Care

- Create a clinic specifically for teens/young adults (perhaps evenings or Saturday mornings)
- Have an "adult" doctor staff the teen clinics (once a month, weekly) for youth to establish a relationship with this provider before the transition
- Establish a Med-Peds care model
- Have co-located clinic setting



Interdisciplinary Team

- Physicians
- ARNPs
- Nurses
- Social Workers
- Case Managers
- Psychologists
- Dietitians
- **Peer Educators/Advocates**
- **Community Advisory Board**

LIFE SKILLS EDUCATION TOPICS

- Anger Management
- Handling Stress
- I'm So Blue…What to Do
- Navigating Health Care System
- Keeping Healthy
- Sexual Activity Factors
- Street Drugs: What They Do To Us
- Communication Skills
- Writing Skills
- Getting the Right Job
- Building Job Interviewing Skills and Resumes
- Our Money: How Can We Make It Last

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Perceived Facilitators of "Successful" Transition

- Patient maturity
- Patient independence
- Strong support system
- Matching patient to adult provider/clinic
  - Confidentiality
  - Access – location, transportation
  - Sexual orientation both of patient and clinic population
- A single contact person at the adult clinic
- Case management follow-up after transfer
- Flexibility in process

***Needs proper evaluation still**

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Issues Impacting Care

- HIV knowledge
- Substance abuse
- Educational achievement
- Mental health
- Housing
- Transportation
- Financial assistance
- Legal/juvenile justice involvement

LESSONS LEARNED

- Knowledge gap exists among adolescents regarding transition.
- Esteem and confidence issues in youth patients remain.
- Decreased medical appointment adherence often due to atmosphere and style of engagement found in adult clinic settings.
- Uncertainty about insurance eligibility, financial concerns, and service rules must be addressed.
- Need for ongoing evaluation!

Where to Begin…(providers)

- Develop a program transition protocol
- Identify appropriate adult care providers who are comfortable with the developmental age group and familiar with chronic diseases of youth
- Consider providing in-service education to adult providers on developmental and behavioral aspects of youth

…how to continue

- Consider patient-specific issues
- Include youth in transition policy development
- Establish client focus groups
- Develop a "Life Skills" curriculum
- Formulate and implement screening tools

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Transitioning HIV+ Youth From Adolescent to Adult Services

Adolescent Provider Toolkit

Funding for this program is provided under Cooperative Agreement # 1 U66HA10313-01-00

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TABLE OF CONTENTS

TITLE PAGE

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Sample Recruitment Flier

Tool #12

Become a Mentor for an HIV+ Young Adult!

Transitioning from Adolescent to Adult Care can be Difficult – You Can Help!

Are you:

- Someone who has Already Transitioned?
- A Caring Clinic Volunteer?
- A Clinic Worker?
- A Carina Community Volunteer?

Contact the Adolescent Clinic to Apply to be a Mentor!

Help a Youth Transition Successfully into Adult HIV Care and Improve Lives

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5 TAKE HOME TIPS

- **Have a structured plan in place.**
- **Discuss transition early on.**
- **Offer options.**
- **Work with "appropriate" adult providers.**
- **BE FLEXIBLE!**

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SUMMARY

Need to celebrate transition successes

•Normalize transition as an expected part of developmental and care processes
•Provide anticipatory guidance with regards to culture of adult health care centers
•Keep in mind long-term survival and quality of life as adult

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Thank you…..questions?

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