Transitioning Youth to Adult Care: Successful Practices from New York State

Introduction

- Madeleine Schlefer. Program Assistant, New York State Department of Health AIDS Institute, Office of the Medical Director

Panelists

- Mary Ellen Adams, RN. Program coordinator for the Maternal Child Adolescent Treatment Services in the Albany Medical Center Department of Pediatrics.
- Alice Myerson, PCNP, ANP. Clinical Coordinator of the Adolescent AIDS Program at Montefiore Hospital

Disclosures

Alice Myerson and Mary Ellen Adams have 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

By the end of this session, participants will be able to:

- Understand crucial steps and actions that should be taken throughout the transition process such as identifying an adult provider, developing a transition plan with the adolescent, helping the adolescent develop the necessary life and health management skills to transition, while avoiding the feeling of abandonment.
- Learn about specific activities, tools, and methods used by different programs in New York State.
- Have the opportunity to discuss how the transitional care models presented by the panel can be implemented by cross-functional healthcare teams or individual team

What We Mean When We Say Transition

"Transition is the purposeful, planned movement of adolescents and young adults with chronic physical and mental conditions from child-centered to adult-oriented health care systems."[1]

1. Robert Blum, Society of Adolescent Medicine 1993 Position Paper

Why Think about Transition

- There is an increasing number of HIV-infected young people growing into adulthood.

Year	Number of 13-19 year olds living with HIV/AIDS in NYS	Number of 20-24 year olds living with HIV/AIDS in NYS
2005	1,836	2,224
2006	1,488	1,967
2007	1,854	2,744

New York State HIV/AIDS Surveillance Semiannual Reports.
http://www.health.state.ny.us/diseases/aids/statistics/semiannual/index.htm

Why Think about Transition

- A smooth, uninterrupted transition from adolescent to adult care allows patients to remain in care and to receive continuous care. Continuity of care and retention in care have both been linked to better health outcomes[2-4].

2. Horstmann, Brown, et al. Clinical Infectious Diseases 2010; 50:752–761
3. Giordiano, Gifford et al. Retention in care: a challenge to survival with HIV infection. Clinical Infectious Disease . 2007; 44(11):1493-9
4. Hecht, Wilson, et al. Optimizing Care for Persons with HIV Infection. Annals of Internal Medicine. 1999; 131(2): 136-143

Alice Myerson, PCNP, ANP

Adolescent AIDS Program
Children's Hospital at
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20 Years of Leadership
A LEGACY OF CARE

Treatment Goals for HIV + Youth

- To empower HIV+ youth to take control of a chronic and potentially fatal illness.
- To provide HIV+ youth with the skills they need to enter into adulthood with a chronic illness

Transition is a process

- The concept of transition is introduced when the client first enters care
  - "….our goal is to give you the skills you need so that when you are 24 you will transition into an adult program…."
  - Each discipline describes its approach to client needs.
- Establishes the potential for growth
- Establishes hope and a sense of future
- Establishes boundaries and roles of members of multidisciplinary team

Skills include

- Finding a voice
  - Describing and acting on symptoms
  - Making decisions
- Quarterly monitoring
  - Learning to schedule and keep appointments
- Adherence to antiretroviral therapy
  - Integrating pill taking into other activities of daily living
  - Pharmacy skills
- Management of insurance

Finding a Voice: Decision Making

- Built on the client's ability to integrate his/her diagnosis into psychological make up and activities of living a full life
- Built on foundation of respect by providers even when client makes "bad" decisions
- Two most important decisions:
  - Choices regarding management of illness, particularly starting and staying on antiretroviral therapy
  - Choices regarding relationships, disclosure and reproductive health

Relationship Building: The Challenge of Engagement and Transition

- Prescriptive model of pediatrics vs. collaborative model of adult medicine
- Bringing in – holding on – letting go
- Attachment vs. dependence
- Separation vs. rejection
- Acknowledgement of meaning of relationship
- Positive past relationship provides the building blocks for future relationships

Markers of Success: 1/10 – 7/10

- 14 clients transitioned into adult care
- 13 had final/termination visits
- Engagement in care in Adult Programs
  - 11 have gone to at least one visit in an Adult Program
  - 2 were scheduled but missed appointments
  - 1 lost to follow up
- On antiretroviral therapy
  - 7 on meds with undetectable viral loads
  - 5 ARVs not indicated
  - 2 prescribed but not adherent

Mary Ellen Adams, RN

Maternal Child Adolescent Treatment Services (MCATS) at Albany Medical Center
Albany, NY

20 Years of Leadership
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Maternal Child Adolescent Treatment Services Albany Medical Center

- HIV specialty care & support services from birth to 24 yrs.
- Exposed & infected; perinatal & behavior acquired; pregnant
- Large geographic area of upstate New York
- Team coordinates care with community providers
- All staff have role in transition process

Transitioning Process: Developing the Resources

- Identify community options: allows for choices
- Educate community providers about adolescents with HIV: improves quality of care
- Participate in community networks to establish linkages & advocate for adolescent issues: increases community support

Transitioning Process: ***Pediatrics***-Adolescent-Adult

- Sequential skills development: early start allows for reinforcement
- Enlist caregiver's support: facilitates the family's transition
- Assess disclosure status/plan: promotes involvement in health care
- Identify learning disabilities: allows for appropriate education & support

Transitioning Process: Pediatrics-***Adolescent***-Adult

- Plan transfer date together, far ahead: no abandonment
- Separate transitions of primary & specialty care: less stress
- Determine preferred model of care (HIV program vs Primary care + ID specialist): increased comfort
- Identify practical options for services: fewer barriers
- Allow to safely experience consequences: reduce enabling

Transitioning Process: Pediatrics-Adolescent-*Adult*

- Flexibility is essential
- Provide personal history letter: fills in gaps of knowledge
- Provide file folder, wallet card of phone numbers, privacy card: encourages organization
- Attend 1st adult visit: Backup for history, learning issues
- Be available for assistance & verify care: identifies barriers & facilitates retention in care

Lessons Learned

- Staff *TRAINING* integral in shift from ped to adolescent focus: promotes provider comfort & improves care
- *CASE CONFERENCES* highlight individual needs/plan: promotes consistent language, education, goals
- *COGNITIVE ASSESSMENTS* inform realistic expectations: promotes appropriate support services
- Expect *DEMONSTRATION* of independence skills: promotes confidence and learning opportunity
- *REVIEW* info with appropriate language for individual: builds on simpler knowledge to increase understanding

The Road to Successful Transition

- Baby steps expected and accepted
- Applaud all successes
- Expect & be there for the steps backward
- Acknowledge the sadness of leaving ped/adolescent staff and excitement of becoming an adult
- Maintain & instill hope, humor, perseverance!

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