Transitioning Children with Chronic Diseases: How do we get there? Perspectives and Challenges from LifeSpan IPC

Lawrence B. Friedman, MD
Professor of Clinical Pediatrics
Director, Division of Adolescent Medicine

Ofelia A. Alvarez, MD
Professor of Clinical Pediatrics
Medical Director, Pediatric Sickle Cell Program

Jayanthi Chandar, MD
Associate Professor of Clinical Pediatrics
Background and Significance

• Approximately 13% of 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
Health care transition is a **purposeful, planned process** 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.

*Blum et al., 1993*
SELECTED REFERENCES


Who is an Adolescent?

- AAP: 12-21 years old
- SAM: 10-24 years old
- APA: 10-18 years old
- AMA: 11-21 years old
- WHO: 10-19 years old

In general: second decade of life, time between “childhood” and “adulthood.”
Adolescents are:

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

- **Body image concerns/puberty**: early adolescence mostly, cognitive changes begin
- **Independence/emancipation**: ongoing throughout, risk-taking behaviors during middle adolescence
- **Identity formation (including sexual identity)**: ongoing throughout
- **Future orientation/delineation of functional role**: late adolescence mostly, mortality issues

**Processes are universal and consistent**
Home

Florida Health and Transition Services (HATS)

Welcome to the FloridaHATS Web site! FloridaHATS is a collaborative initiative of the Florida Department of Health, Children's Medical Services Managed Care Plan and other partners throughout the state.

Our Mission

To ensure successful transition from pediatric to adult health care for all youth and young adults in Florida, including those with disabilities, chronic health conditions or other special health care needs.

Our Vision

All youth in Florida will successfully transition to every aspect of adult life, including adult health care, work, and independence.

Our Values

Youth and young adults will:

1. Participate in decision-making at all levels, and be satisfied with the services they receive,
2. Receive coordinated, ongoing, comprehensive care within a medical home,
3. Have adequate private and/or public insurance to pay for the services they need,
4. Be continuously screened to detect other conditions and prevent secondary disabilities,
5. Access community-based systems that are integrated, collaborative, and organized so they can be easily used, and
6. Will receive services that meet their physical, social, and developmental needs.
“...people have different ideas of what transition even means and we probably spent let’s say two years just talking trying to teach the difference between transfer and transition.”

“[some providers] focus more on transfer than transition where the job was to simply get them an appointment at the clinic rather than teach them how to call the clinic and arrange that themselves.... I called, I got an appointment so it is done.”
Importance of Planning

• HCT doesn’t happen automatically

• Young adults with disabilities and special health care needs often require ongoing medical care

• Expertise of care 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
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
TRANSITIONING YOUTH INTO ADULT CARE

SUCCESSFUL STRATEGIES

- Pediatric provider recommends adult provider options
- Pediatric provider offers youth medical history
- Mentors/Buddies
- Youth becoming 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 overseeing transition process
Experiences / Practices

Minimal attention to preparing youth:

• Improving communication skills
• Describing own medical condition or special needs
• Taking medication/treatment independently
• Knowing legal rights
• Learning about health insurance
• Accessing community resources
Pediatricians: Other Barriers

• **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
  • Lack of transportation
Limitations of Adult Providers: Contributing Factors

1. Managed care guidelines
2. Low reimbursement rates
3. Time required
4. Communication barriers
5. Lack of resources/supports
6. Lack of information about existing community agencies/services
7. Limited training and experience

8. “Word of mouth” resulting in overwhelming numbers of medically complex patients

9. Design of medical facilities:
   - Lack of ADA-compliant equipment
   - Non-accessible spaces
   - Waiting room issues
Youth and Families: Barriers

1. Not well-informed or prepared about adult service systems:
   - Fewer available programs
   - Stricter eligibility criteria
   - Increased financial burden
   - Termination of childhood support systems

2. Medical practitioners not proactive in planning for transition
Youth and Families: Barriers (cont)

3. Confusion about available resources

4. Youth not taking responsibility for managing own care

5. Legal implications when youth reach age of majority

6. Communication difficulties

7. Worry about finding a knowledgeable, caring adult provider
Special Adolescent Clinic (for youth acquiring HIV)

- Average of 90 patients enrolled for specialty HIV and primary health care
- Age range 15-25 y/o (NIH research protocols for HIV extended upper limit!)
- Multi-disciplinary and multi-cultural staff members
- Different outcomes than youth with perinatal HIV infection
Interdisciplinary Team

- Physicians
- ARNPs
- Nurses
- Social Workers
- Case Managers
- Psychologists
- Dietitian
- **Peer Educator/Advocate**
- Community Advisory Board
LIFE SKILLS EDUCATION TOPICS

- Anger Management
- Communication Skills
- Writing Skills Workshop
- Getting the Right Job
- Handling Stress
- Navigating Health Care System
- Keeping Healthy
- Building Job Interviewing Skills and Resumes
- Our Money: How Can We Make It Last
- Sexual Activity Factors
- Street Drugs: What They Do To Us
- I’m So Blue...What to Do
Figure 1: SAC Transition of Care Model

PHASE ONE
• Discussions begin with identified clients, regarding the transition process.

PHASE TWO
• Client meets the adult ID physician formally for the first time at SAC.

PHASE THREE
• Client has check up at SAC, conducted by the adult ID physician.

PHASE FOUR
• Client is seen at the adult clinic for first appointment, by the adult ID physician.

PHASE FIVE
• One year follow-up is conducted with client by psychosocial team.

Note: The model displayed depicts the phases of the process for a client transitioning from SAC to an Adult clinic. Arrows portray direction of movement from one phase to the next. As evidenced by the reciprocal arrows between phases 3 and 4 and the disconnected arrow between phases 5 and 4, one can see how clients revert from one phase to another. The arrows emanating from phase 5 show that this is an ongoing process which involves full support of the medical and psychosocial team throughout the entire process.
Perceived Facilitators of “Successful” Transition

• Patient maturity
• Patient independence
• Strong support system
• Matching patient to adult provider/clinic
  • Confidentiality
  • Access – location, transportation
  • Sexual orientation
Perceived Facilitators of “Successful” Transition

• A single contact person at the adult clinic
• Case management follow-up after transfer
  • “Sometimes we are the only family that they have ever known in a long-term relationship. That is just part of the process and I’m not sure [it’s] all bad.”
• Flexibility in process
LESSONS LEARNED

• Need for ongoing evaluation!
• Esteem and confidence issues remain.
• Knowledge gap among adolescents regarding transition.
• Decrease in medical appointment adherence due to atmosphere and style of engagement found in adult clinic settings.
• Uncertainty about insurance eligibility, financial concerns, and service rules.
Transitioning HIV+ Youth From Adolescent to Adult Services

Adolescent Provider Toolkit

Funding for this program is provided under Cooperative Agreement # 1 U69HA 10553-01-00
# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>TITLE PAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction to the Adolescent Provider Toolkit</td>
</tr>
</tbody>
</table>

## Section 1: Transitioning Youth
- Tool #1: Transitioning: What to Expect | 8 |
- Tool #2: Choosing the Adult Clinic | 9 |
- Tool #3: Steps to Developing a Relationship with the Adult Provider | 10 |
- Tool #4: Sample Adolescent/Adult Provider MOU | 11 |
- Tool #5: Clinical Summary Template | 13 |
- Tool #6: Preparing the Youth to Meet the Adult Provider | 16 |
- Tool #7: Setting Program Goals | 17 |
- Tool #8: Transition Program Exit Survey | 18 |

## Section 2: Creating the Young Adult Leader Program
- Tool #9: Who Should Be Involved? | 22 |
- Tool #10: Young Adult Leaders Job Description | 23 |
- Tool #11: Sample Job Description | 24 |
- Tool #12: Sample Recruitment Flier | 26 |
- Tool #13: Screening Potential Volunteers | 27 |
- Tool #14: Sample Interview Guide | 28 |
- Tool #15: Orienting Young Adult Leaders | 29 |
- Tool #16: Making a Match | 30 |
- Tool #17: Facilitating the Match | 31 |

## Section 3: Program Supervision
- Tool #18: Creating a Supervision Plan | 33 |
- Tool #19: Sample Supervision Checklist | 34 |
- Tool #20: Group Supervision Plan | 35 |

## Section 4: Policies and Procedures
- Tool #21: Setting Boundaries | 38 |
- Tool #22: Sample Confidentiality Agreement | 39 |
- Tool #23: Creating a Manual | 40 |
- Tool #24: Policies and Procedures Examples | 41 |

## Section 5: Supporting Young Adult Leaders
- Tool #25: Self-Management Checklist | 50 |
- Tool #26: Life Skills Checklist | 52 |

## Section 6: Young Adult Leader Toolkit and Answer Keys | 54 |
Sample Recruitment Flier

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 Caring Community Volunteer?

Help a Youth Transition Successfully into Adult HIV Care and Impact a Life!

Contact the Adolescent Clinic to Apply to be a Mentor!
Transitioning youth are at risk of dropping out of healthcare or delaying their treatment. The goal of this program is for the adolescent provider, the adult provider, and you, the Young Adult Leader, to support the youth through this transition and help keep their treatment on track. This will support them in living long, healthy lives.

The tools in this section will help you provide the transitioning youth with information and guidance about what it's like to transition.
5 TAKE HOME TIPS

• Have a structured plan in place.

• Discuss transition early on.

• Offer options.

• Work with “appropriate” adult providers.

• BE FLEXIBLE!