Transitioning Children with Chronic Diseases:

How do we get there? Perspectives and Challenges from LifeSpan IPC

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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

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.**

Blum et al., 1993

SELECTED REFERENCES

- Rosen, D. Between two worlds: Bridging the cultures of child health and adult medicine. *Journal of Adolescent Health, 17*(1): 10-16, 1995.
- Position Paper of Society for Adolescent Medicine. Transition to Adult Health Care for Adolescents and Young Adults with Chronic Conditions. *Journal of Adolescent Health;* 33(4): 309-311, 2003.
- AAP, AAFP, ACP: Consensus statement on health care transitions for young adults with special health care needs. *Pediatrics;* 110: 1304-1306, 2002.
- Betz, CL. Transition of adolescents with special health care needs: Review and analysis of the literature*. Issues in Comprehensive Pediatric Nursing, 27*: 179-241, 2004.
- Brumfield, K. & Lansbury, G. Experiences of adolescents with cystic fibrosis during their transition from pediatric to adult health care: a qualitative study of young Australian adults. *Disability and Rehabilitation, 26*(4): 223-234, 2004.

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

Health Care Transition Information and Resource Guide

Hillsborough County Information & Resource Guide

What's Health got to do with Transition?

Moving from pediatric to adult health care

llsborough County
NFORMATION & RESOURCE GUIDE

ATIONAL
LORIDA
ILLSBOROUGH COUNTY
DULT PRIMARY CARE PRACTICES
EHAVIORAL AND MENTAL HEALTH
ENTAL
ATING DISORDERS
QUIPMENT
AMILY PLANNING
LASSES
UARDIANSHIP
EALTH CLINICS
NDEPENDENT LIVING
EDICAL COVERAGE
UBLIC ASSISTANCE
UBSTANCE ABUSE

Healthy & Ready to Work National Center
202-884-8650, www.hrtw.org
A wealth of information, tools, resources, and connections to health care transition experts.

Institute for Child Health Policy
352-265-7220, www.hctransitions.ichp.edu
Listserv, videos, training materials, and other health care transition resources.

Social Security Online
800-772-1213, 800-325-0778 (TTY)
www.ssa.gov/disability
Eligibility information and application for SSI and SSDI disability benefits.

National Guardianship Association
520-881-6561, www.guardianship.org
Resources for family and professional guardians, including newsletters, conferences, and networking opportunities.

The Arc
301-565-3842, www.thearc.org
Guardianship issues are addressed on this Web site.

NATIONAL

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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.

Challenges

"…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**

Limitations of Adult Providers (cont)

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

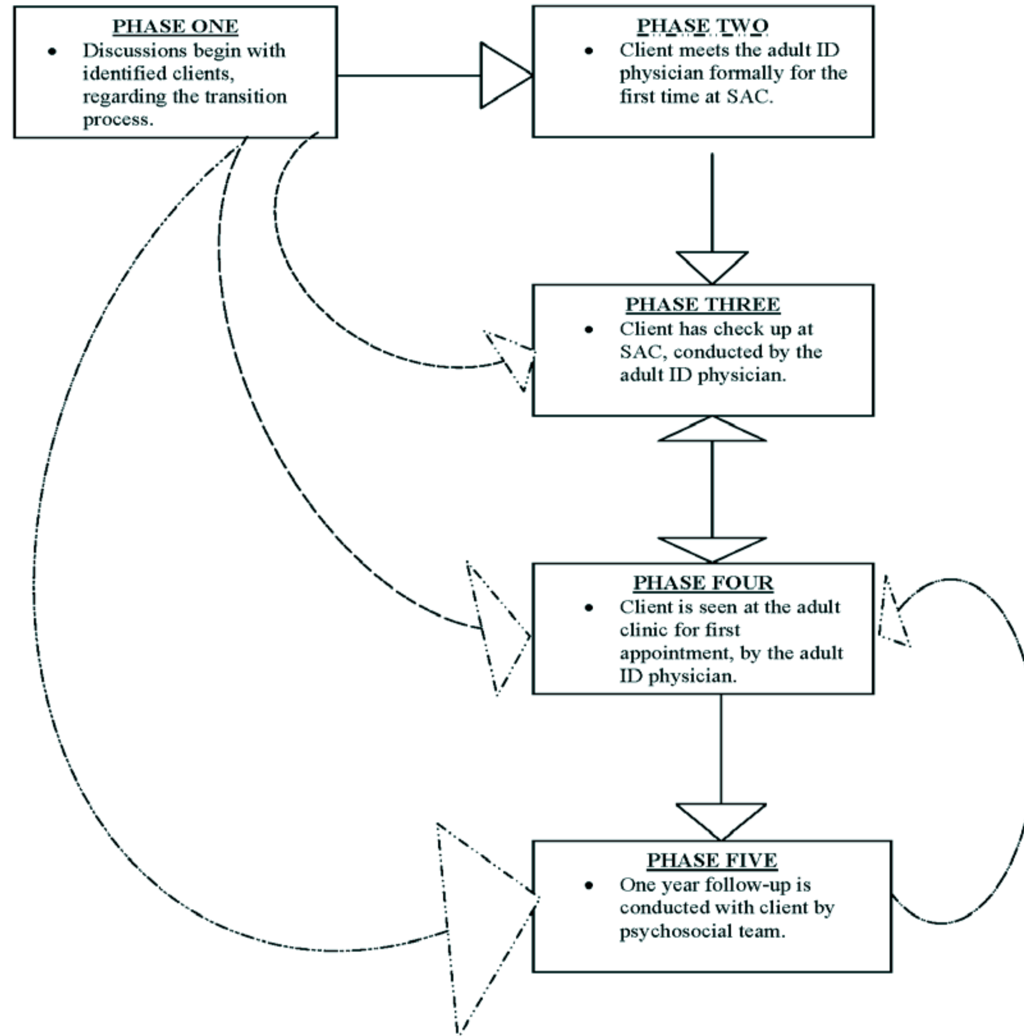
Interdisciplinary Team

- 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



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 1 show that this is an ongoing process which involves the full support of the medical and psychosocial teams 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

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

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Tool #12

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?

Contact the Adolescent Clinic to Apply to be a Mentor!

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

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!**