Preparing Teens for Transition to Adult Health Care:  
10 Steps to Successful Health Care Transition  

Janet Hess, MPH, CHES  
June 7, 2013
Agenda

- Why is it important?
- How are we doing?
- What steps can you take to ensure successful transition?
- How can Florida HATS help?
Health Care Transition (HCT)

The purposeful, planned movement of adolescents and young adults from child-centered to adult-oriented health care systems.

Transition Preparation

Increased responsibility for health care self-management; understanding and planning for changes in health needs, insurance, and providers in adulthood; should occur across ages 12-21+

Transfer of Care

Discrete event, physical transfer from a pediatric to an adult provider; should occur between ages 18-21+
Why is HCT Important?

“A poor transition in health care can threaten health and undermine other transitions, for example in education, work, social relationships, and independent living.”

Source: Institute of Medicine, 2007
Goals for Transition

- Manage their own health
  - Disease self-management
  - Prevention, substance use, safety, sexuality
- Appropriately access adult primary care, specialists, therapies, equipment, supplies, etc.
- Access to adequate and continuous health insurance
- Implement education and vocational goals

How Are We Doing?

MCHB Core Outcome #6: CSHCN age 12-17 years who receive services needed for transition to adult health care, work and independence
CSHCN age 12-17 years only
Nationwide

Outcome successfully achieved: 40.0%
Outcome not achieved: 60.0%

2009-2010 National Survey of Children with Special Health Care Needs
10 Steps to Successful Health Care Transition
#1: Start Early!

Begin preparing for transition even when young.
#2: Focus on responsibility for health care

Taking responsibility for health care should be based on age and abilities. Teens can become more independent by learning important skills like talking to their doctor, asking questions, scheduling appointments, arranging transportation, filling prescriptions and taking medication on their own.
Pediatricians
Child-friendly
Family-centered
Interact primarily with parents
Nurturing
Prescription
Developmental Focus

Adult Physicians
Cognitive
Patient-centered
Interact with patient
Empower individual
Collaborative
Disease Focus
#3: Create a health summary

Put important information about personal health in one place, including medications and plans for emergencies.
#4: Create a health care transition plan

Work with the child’s health care team (e.g., primary care provider, nurse care coordinator, social worker) to develop a written transition plan that includes future goals, services that will be needed, who will provide them, and how they will be paid for.
#5: Maintain wellness

Support good habits that will continue into adulthood. Talk about risky behaviors such as alcohol use and smoking, as well as sexuality and relationships.

Teens should spend time alone with their doctor at every office visit.
#6: Know options for health insurance and public assistance programs in adulthood.
Health insurance after Age 18

- Aging out of health care plans/services (private insurance, state Title V, SCHIP) at age 19 or 21
- Benefits in temporary jobs often limited, unavailable, or high premiums
- Desire to work and be independent may jeopardize dependent status needed to remain on health plan
- Increased salary may lower/eliminate SSI payments
- Limited benefits provided in adult Medicaid package
Impact of Affordable Care Act

Effective in 2010:

- Young adults up to age 26 can enroll in parents’ private insurance plan, regardless of marital status or living situation, if they aren’t eligible for any other employer-sponsored plan
- **3.5 million more YA on parents’ plan since 2010!**

Effective in 2014:

- Extends Medicaid coverage up to age 26 to foster care children
- For some states, expands Medicaid eligibility
- Increase Medicaid reimbursements for some PCPs to Medicare level
- Creates state-based health insurance Exchanges to provide more private options; enrollment starts in October 2013
- Pre-existing conditions covered
#7: Find Adult Providers

If still in the care of pediatric providers, identify a primary care physician and specialists who provide care for adults.
Lack of Available Adult Providers

Who are:

- Trained in pediatric onset conditions
  - Primary and specialty care
- Willing to take primary responsibility for care
- Provide developmentally appropriate services for low functioning young adults
- Accept Medicaid
By Age 17, Ask 3 Questions of Physician

1. At what age should (I/my child) transfer to adult primary and specialty care providers?
2. Can you help us identify appropriate providers?
3. Can you communicate with the new providers and provide a transfer summary?
#8: Include health in other areas of transition

Ask the teen’s primary care physician to provide documentation of medical conditions and special health care needs for other programs and agencies.
#9: Integrate HCT activities in the student’s IEP or 504 Plan
Transition IEP Factors

- Understanding own needs and required accommodations
- Accessibility, such as entrances, school activity areas, transportation, emergency evacuation
- Stamina and strength issues, such as carrying heavy books, scheduling classes
- Medication, medical supplies, and equipment
- Volunteer experiences and recreational activities to develop work and social skills
Transition IEP Factors

- Self-determination, self-advocacy
- Vocational training that won’t conflict with health needs
- Modifications to physical education program
- Classroom seating, such as avoiding being next to windows because of allergies or noise
- Health care management skills, self-care, and knowledge of health insurance
- Special dietary needs
#10: Learn about community services and supports for adults

Be knowledgeable about rights and responsibilities at age 18!
Discuss guardianship and decision-making options, as needed.
Florida’s clearinghouse for health care transition information at www.FloridaHATS.org
Florida Health and Transition Services

- Program established in 2009
- Positioned in the Department of Health, Children’s Medical Services (state Title V program)
- Administered by USF Pediatrics and UF-Jacksonville
- Implement a state HCT plan
Home

Florida Health and Transition Services (HATS)

Welcome to the FloridaHATS Web site! FloridaHATS is a collaborative program of the Florida Department of Health, Children’s Medical Services Network, Florida Developmental Disabilities Council, 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.

See Florida’s Strategic Plan for Health Care Transition in a one-page visual or in the comprehensive 2009 Task Force Legislative Report. For a complete description please visit our About page. >>

What’s New?
For Youth & Families

FloridaHATS Information Guides

- FloridaHATS Brochure in English, Spanish, and Haitian Creole
- 10 Steps to Successful Health Care Transition (a short guide in Spanish/English and Creole/English)
- Algorithm for YSHCN in Florida (decision-making tool for preparation for transition to an adult model of care)

*From the Institute for Child Health Policy at the University of Florida, and CMS:*

- Envisioning My Future (English) (Spanish)
- Since You’re Not a Kid Anymore (Spanish rev 12-10) (Spanish rev 12-10)
- Now That You’re in High School (English rev 12-10) (Spanish rev 12-10)
- When You’re 18 (English rev 9-11) (Spanish)

*From the University of South Florida:*

- What’s Health Got To Do with Transition? (English) (Spanish)

Transition Toolkit

**NEW!** An easy-to-use, interactive Transition Toolkit for physicians, families and youth, case managers, and teachers. Through a series of questions, the toolkit helps you determine which resources may be most useful (depending on your role) to support the transition process. Developed by the JacksonvilleHATS Coalition, the Toolkit incorporates instruments and resources that have been adapted for Floridians but can be used by anyone. Get started here!

Transition 2 Go

**NEW!** Introducing the first in a series of informational briefs with transition-related tips and resources for health care providers in Florida:

- T2G_Health Insurance
- T2G_Employment
- T2G_Medicaid Waiver
- T2G_Guardianship
Health Services Directory for Young Adults

Use the form below to search for health care programs and providers in your area that serve young adults, including those with disabilities or chronic health conditions.

Providers: For instructions on adding a service to our service directory or updating an existing entry, please visit our Submission Instructions page.

Disclaimer: A listing in this directory does not imply an endorsement from FloridaHATS, Florida Developmental Disabilities Council, Florida Department of Health, or Children’s Medical Services. The information is solely for your convenience in locating services from those available in your area. Individuals should perform their own research of any organization they choose. If the service is covered on an insurance plan, first check the plan’s provider network. However, if you believe a particular listing in this directory does not meet our criteria of serving young adults with chronic health conditions or disabilities, please contact us here.

Search By: Categories AND/OR Keyword(s)

City, State, County: [Any City]
County: [Any County]
Health Category: [Any Health Category]
Search by Keyword(s):

[Submit Query] [Reset]
10 Steps to Successful Health Care Transition

Success in the classroom, within the community and on the job requires that young people stay healthy. The best ways to stay healthy are to understand your health, participate in health care decision making, and receive age-appropriate care. Here are 10 ways to ensure a smooth transition from pediatric to adult health care for teens and young adults with disabilities or chronic health conditions.

1. Start early! Begin preparing for transition even when very young, like starting a health summary and talking about health needs.

2. Focus on responsibility for health care. Taking responsibility for health care should be based on age and abilities. Become more independent by learning the skills for managing health care, like scheduling appointments, arranging transportation, taking medication, filling prescriptions, and talking to doctors.

3. Create a health summary. Put important information about personal health in one place, including medications and plans for an emergency.

4. Create a health care transition plan. Work with your primary care provider to develop a written health care transition plan that includes future goals, services that will be needed, who will provide them, and how they will be paid for.

5. Maintain wellness. Support good habits that will continue into adulthood! Talk about risky behaviors such as alcohol use and smoking as well as sexuality and relationships. You can ask to speak to your physician alone.

6. Know options for health insurance and public assistance programs in adulthood. If you’re unsure about eligibility, it’s always best to go ahead and apply.

7. Find adult providers. If still in the care of pediatric providers, identify a primary care physician and specialists (including mental health professionals) who work with adults.

8. Include health in other areas of transition. Ask your primary care physician to provide documentation of medical conditions and special health care needs for other programs or agencies, as needed.

9. Integrate health care transition activities in the student’s Individualized Education Plan (IEP) or 504 Plan. Consider self-determination and self-advocacy skills, understanding personal health conditions and needs, and health care self-management skills.

10. Learn about other community services and supports for adults. Be knowledgeable about rights and responsibilities at age 18!

Visit www.FloridaHATS.org to view in large print
Para español, visite nuestro sitio web.
Pour l’anglais, consultez notre site web.

June 2011
Guardianship and Alternatives for Decision-Making Support

Floridians aged 18-30 who have intellectual disabilities, ages or health care transitions face significant questions for healthcare providers and families about guardianship. This brief provides a broad overview of guardianship and other decision-making supports as well as resources that will provide more in-depth information.

Guardianship Issues

Reaching the age of 18 - Opportunities and Challenges for Young Adults with Disabilities

Reaching the age of majority (18 years) in most states is a major milestone. By 18, an individual is considered an adult. As adults, people have the right and responsibility to make certain legal choices that adults make. For some young adults with intellectual disabilities, this is an exciting opportunity for increased independence. However, there may also be family concerns about how to best support that person’s self-determination in making life decisions such as health care or institutional management.

This brief provides a broad outline of decision-making support options, both informal and formal. Each state and jurisdiction has different laws and options. Each state and jurisdiction has different laws and options. This brief includes an overview of the process of guardianship, its role in decision-making, and the important role it plays in supporting young adults with intellectual disabilities.

Decision-Making - A Skill That Requires Practice and a Variety of Experiences

Decision-making is a learned skill. Children and youth who have support and experience making important choices, such as choosing a school, will approach adulthood having developed this skill. Without developing these skills, young adults may struggle with decision-making. This brief provides guidance on how to develop these skills, including practice in decision-making, problem-solving, and critical thinking.

Supplemental Security Income (SSI) and Guardianship

SSI is a federal program administered by the Social Security Administration (SSA) that provides cash assistance to individuals who meet the eligibility requirements for need-based benefits. SSI benefits are designed to help individuals who are unable to work due to a disability.

The transition to adulthood can be challenging for individuals with intellectual disabilities, and SSI benefits can provide financial support during this transition. However, it is important to consider the impact of SSI on other benefits that an individual may be eligible for, such as Medicaid or Medicare.

For more information about SSI and guardianship, please contact your local SSA office or your state’s Developmental Disabilities Council. Additionally, many states have programs and services available to support individuals with intellectual disabilities during the transition to adulthood.
What’s HEALTH
Got To Do with TRANSITION?

CURRICULUM

Transition for Students with Disabilities
How Parents Can Be Effective Advocates in the IEP Meeting

HILLSBOROUGH COUNTY PUBLIC SCHOOLS

Moving from Pediatric to Adult Health Care

Scheduling an appointment

Getting health insurance

Parent/Student Handouts

Links to Videos/ Lesson Plans
A Guide to the Florida Juvenile Justice System for Parents of Youth with Disabilities or Chronic Health Conditions

Developed by FloridaHATS and Project 10 in partnership with Florida Department of Juvenile Justice, Florida Department of Education, and Florida Department of Health, Children’s Medical Services

June 2012
Health Insurance

School to Work Transition Vocational Rehabilitation

Transition planning for individuals whose health conditions interfere with their ability to work should address eligibility for an array of VR programs, including the School to Work Transition program. The School to Work Transition program specifically helps students ages 16-22 prepare for employment and adult life. VR transition activities can help students enter training, continue education, and find a job after leaving high school.

For more information about this topic, contact Janet Hess at jhess@health.ufl.edu or (813) 259-8604.

Issue no: 2

September 2012

Guardianship and Other Decision-Making Alternatives

Reaching the age of majority – 18 years old in Florida – means an individual is no longer a “minor.” As such, the person has the right and responsibility to make certain legal choices that adults make, for some youth with disabilities, this may be an exciting opportunity for increased independence. But there may also be family concerns about how to best support that person's self-determination in making life decisions such as for healthcare or in financial management.

Many parents and caregivers are surprised to learn that when their child turns 18, they may not be able to directly participate in their child's medical treatment, except as a proxy during an emergency. Further, banks and government agencies have neither the duty nor the authority to discuss an 18 year old's financial issues with parents. Families often ignore the problem, fearing the expense or complexity of court, and carry on with only minor difficulty until confronted by an emergency. But when an emergency finally occurs, their fears of expense and complexity may be realized.

There are several levels of healthcare and financial decision-making assistance available to Floridians, ranging from informal “shared” responsibilities with a trusted friend or family member, to health care surrogacy, durable power of attorney or guardianship. State law requires, whenever possible, the use of the least restrictive alternative to protect persons incapable of fully caring for themselves or managing their affairs. Some families may find that “guardian advocacy” is a good option for individuals with an intellectual or developmental disability. This process delegates several rights of the individual to another person (such as a parent) without declaring them incapacitated (see www.careoptions.ufl.edu/guardianship). For a full list of options for people with IDD, visit www.descrd.org/dvwa/guardianship.html.

Certainly, cost for legal services – which can exceed $5,000 for guardianship - is a concern for most families. However, income-eligible consumers may qualify for zero-fee or reduced-fee services through Florida Legal Services, a statewide network of organizations that provide legal assistance based on need (see http://www.legalcutethread.com). The Center for Guardian Advocacy offers a sliding fee scale, the Florida Bar operates a lawyer referral service at 877-DOC-FLOR.

For more information about this topic, visit the Tool Box at www.FloridaHATS.com or contact Janet Hess at jhess@health.ufl.edu, (813) 259-8604.

Issue no: 4

December 2012

Home and Community-Based Living Medicaid Waivers

For more information, visit www.myfloridahats.org.
Training for Health Care Professionals

Are you a professional looking for FREE continuing education credits on a health care topic that really matters to your adolescent and young adult patients and their families?

Health Care Transition Training Program

Training Program Overview

This online training curriculum includes information about how professionals can help prepare youth with chronic health conditions and disabilities for their eventual transition from pediatrics and transfer to adult care.

Contents of Module 1:
- Introduction to the Offered Curriculum
- "Preparing the Young Adult for Adult Health Care" workshop
- "What is Health Care Transition?"
- "What is Adult Health Care?"
- "Transition: Stages and Issues"
- "Adult Health Care in Transition"
- "Healthcare and the Adult Transition"
- "Who Is the Young Adult Health Care Transition Provider?"
- "Education and the Adult Transition"
- "Transition to Vocational Rehabilitation"
- "Legislation for Transition" 7 Credits* per module. Each program should take credit course content with the extent of their participation in the activity.

Contents of Module 2:
- "College and Beyond"
- "Developmental Needs of Health Care and Child-Adult Professional Relationships"
- "Transition to Education: Transition Planning Tools"
- "Transition to Vocational Rehabilitation"
- "Legislation for Transition" 7 Credits* per module. Each program should take credit course content with the extent of their participation in the activity.

Accreditation

The four-hour long Health Care Transition Training Program is broken down into two two-hour modules. The accreditation statement below applies to each module for a total of four contact hours.

Physicians: This activity has been planned and implemented in accordance with the accreditation requirements and policies of the Accreditation Council for Continuing Medical Education through the joint sponsorship of the Florida AHEC Network, the University of Florida College of Medicine, the Florida Department of Health, and the School of Medicine, University of Florida. The Florida AHEC Network is accredited by the Florida Medical Association to provide continuing medical education for physicians. The Florida AHEC Network designates this educational activity for a maximum of 2.0 AMA PRA Category 1 Credits. Each module is worth four credits. Each program should take credit course content with the extent of their participation in the activity.

Certified Case Workers: The Florida Board of Certified Case Workers approved provider: BAY 590 is an approved provider of continuing education. This program offers the requirement for up to 2.0 contact hours each for two modules.

Nurses: The Florida Board of Nursing approved provider: RN 590 is an approved provider of continuing education. This program meets the requirements for up to 2.0 contact hours each for two modules.

Social Workers: The Board of Social Work approved provider: SW 590 is an approved provider of continuing education. This program meets the requirements for up to 2.0 contact hours each for two modules.

This program is presented by the Florida AHEC Network and the University of Florida Department of Health.

www.ahecdesi.com
Conditions

- Janet Hess, MPH, CHES
  FloridaHATS Project Director
  University of South Florida
  jhess@health.usf.edu, (813) 259-8604

- David Wood, MD, MPH
  CMS Statewide Medical Consultant for HCT
  UF College of Medicine-Jacksonville
  david.wood@jax.ufl.edu, (904) 244-9233

www.FloridaHATS.org