Florida HATS: Building Bridges from Pediatric to Adult Care

October 14, 2014
Health Care Transition

**Health Care Transition (HCT)**
The purposeful, planned movement of adolescents and young adults, with and without SHCN, from child-centered to adult-oriented health care systems.

**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+

**Successful Transition**
Patients are engaged in and receive on-going patient-centered adult care.
Florida Strategic Plan for HCT

- Health Care Financing
- Education and Training
- Advocacy
- Service Delivery Systems
A Public Health Approach

Vertical and Horizontal Integration Model for Health Care Transition in Florida

Federal
- MCHB/Title V
- Got Transition
- HP 2020
- SAM
- AAP
- AAFP
- ACP

State
- DOH/CMS
- AHCA
- APD
- FDDC
- DCF
- DOE
- Project 10

Community
- Primary & Specialty Care
- Hospitals Clinics FQHCs
- CHD
- CIL
- Mental Health
- Social Services
- School District

Family
- Y/YA
- Parents/Caregivers
- Circle of Support
Graduating from pediatric to adult care
FloridaHATS
Health and Transition Services

HillsboroughHATS

www.FloridaHATS.org
Clearinghouse of HCT Information
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. You can become more independent by learning important skills like talking to your doctor, asking questions, scheduling appointments, arranging transportation, filling prescriptions and taking medication on your own.
Pediatricians
Child-friendly
Family-centered
Interact primarily with parents
Nurturing
Prescription
Developmental Focus

Adult Physicians
Expectations for mature patients
Patient-centered
Interact with patient
Empower individual
Collaborative
Disease Focus
Self-Management Videos

Short Videos with step-by-step instructions
#3: Create a health summary

Put important information about personal health in one place, including medications and plans for emergencies.
My Health Passport

If you are a health care professional that will be helping me, PLEASE READ THIS
before you try help me with my care or treatment.

My full name is: ____________________________
I like to be called: __________________________
Date of birth: __/__/____
My primary care physician: ____________________
Physician’s phone number: ____________________

This passport has important information so you can better support me when I visit/stay in your hospital or clinic. Please keep this with my other notes, and where it may be easily referenced.

My signature: ____________________________ Date completed: __/__/____
You can talk to this person about my health: ____________________________ Relationship: ____________________________

I communicate using: (e.g. speech, preferred language, sign language, communication devices or aids, non-verbal sounds, also state if extra time/support is needed)

My brief medical history: (include other conditions (e.g. visual impairment, hearing impairment, diabetes, erysipelas) past operations, illnesses, and other medical issues)

My current medications are:

When I take my medication, I prefer to take it with:

How I cope with medical procedures: (e.g. how I usually react to injections, tests, physical examinations, x-rays, magnetic therapy—also note procedures never experienced before or in recent years)

I am allergic to the following:

If I am in pain, I show it by:

My mobility needs are:

When getting washed and dressed, you may assist me by:

My favorite foods and drinks are:

I do not like to eat or drink the following:

When drinking, you may assist me by:

I am very sensitive to specific foods, sounds, colors, textures, or scents that I usually dislike (e.g. fluorescent lights, fluorescent bulbs, loud noise, etc.)

Things I like to do that will keep pass the time:

How to make future/follow-up appointments easier for me:
(e.g. give me the medical appointment of the day, let me know for the appointment of the day following my appointment, give information to my caregivers, etc.)
#4: Create a health care transition plan

Work with your 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.
Welcome

This Transition Toolkit was designed to provide a step-by-step approach to accessing resources that will help you with transition from pediatric care to adult care. The toolkit is designed for pediatric providers, other health care personnel (e.g., social workers, nurse care coordinators) and patients & families. The resources provide guidance or information to support youth and families during transition to adulthood and to adult health care. You will be asked a series of questions that will help determine which resources will be most useful to you (depending on your role) to support the transition process.
#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 should spend time alone with your doctor at every office visit.
Self-Advocacy Guides

1. **Since You're Not a Kid Anymore**
   - It's time to be more in charge of your health
   - Health Care Transition Guide for Teens in Middle School

2. **Now That You're in High School...**
   - It's time to be more in charge of your health
   - Health Care Transition Guide for Teens in High School

3. **When You're 18**
   - You are in charge of your health
   - Health Care Transition Guide for Young Adults
#6: Know options for health insurance and public assistance programs in adulthood.
Plan for change in insurance coverage

- Medicaid
- Parents’ plan
- Employer-based
- Marketplace plans
#7: Find Adult Providers

If still in the care of pediatric providers, identify a primary care physician and specialists who provide care for adults.
ASK THEM 3!

All teens and their families should ask their pediatric doctors these 3 questions:

1. When should I/my child transfer to adult primary and specialty care physicians?
2. Who should I/my child go to for adult primary and specialty care?
3. Will you help with the transfer of care by communicating my/my child’s needs and providing a transfer summary?

Health Services Directory for Young Adults
Search for services and programs by community, county, key word or type of service.

For additional information and assistance with resources in Hillsborough County that support transition from pediatric to adult health care, please contact:

Joane White, Family Support Worker
Children’s Medical Services
(813) 396-9772
Joane_White@doh.state.fl.us
#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 and agencies.
School to Work Transition
Vocational Rehabilitation

Most teens and young adults look forward to having a job and being independent. For young Floridians with disabilities whose goals include employment, the Florida Department of Education's Division of Vocational Rehabilitation (VR) can provide critical support services. This federal-state program works with people who have physical or mental disabilities to prepare for, gain and/or retain employment.

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/or find a job after leaving high school.

Any student with a disability may be eligible for VR services starting when students receive special education services, schools often refer to VR as part of the student's transition individualized education program. However, having an IEP is not a VR eligibility requirement. Health care providers can assure that all young people with disabilities and their families are made aware of VR as a potential source of services and supports, and facilitate appropriate referrals as needed.

Students who may benefit from VR services should apply at least 1 year before leaving high school, e.g., apply at age 16 if leaving high school at age 17. VR services include individualized, community-based work experience while they are still attending school. Applications can be downloaded at http://rehabworks.org/docs/6346265.pdf and VR referrals can be made by anyone by contacting the local VR office or www.rehabworks.org (click on VR Office Directory). To learn more, contact the Transition program at www.rehabworks.org/docs/6002208.

For more information about this topic, contact Janet Hess at jjhess@health.state.fl.us or (813) 259-8601.

Home and Community-Based Living Medicaid Waivers

Home and Community-Based Services (HCBS) Waivers are Medicaid programs that provide services in the home for those who have a developmental disability or a diagnosis of mental illness, in a less restrictive setting than traditional care in a psychiatric hospital. These services are given in the person's home or in a community-based setting.

Supplemental Security Income (SSI): What happens to my SSI when I turn 18?

Tip Sheet 3  April 2011

Tip Sheet 3

- The answer is no, it depends; you need to re-apply
- Social Security will review your case
- Since you are not a child anymore, you will need medical evidence to prove that you are disabled as an adult
- Yes, you can work
- For every $2 you earn, Social Security will deduct about $1 from your SSI check
- If you earn enough so that there is no money left to deduct from your SSI check, you may still be able to keep your Medicaid (depending on how much you earn)
- Yes, Social Security has other ways to help you keep more of your SSI check if you are earning money
- If you are under age 22 and regularly attending school, Social Security won't count up to $6,000 of earnings before deducting from your benefit check
- Social Security will let you save money for college or training, a computer, and other expenses by helping you write a plan to achieve self-support (PASS Plan)
- There are other deductions and programs to help you, too

Appeal your case

- You may continue getting your SSI check if:
  - Social Security has approved your participation in a vocational rehabilitation or similar program
  - You have told Social Security that you are currently participating in an Individualized Education Program (IEP)
  - You must participate in these programs before Social Security turns you down and at least 2 months afterwards

For help, contact the Work Incentives Planning and Assistance (WIPA) Program in your state. The contact information can be found on the Social Security website by clicking on the Service Provider Directory link at https://secure.ssa.gov/appss/10/sep/providers.aspx?state=

Visit us online at http://labs.umassmed.edu/transitions RTC

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#9: Integrate HCT activities in your Transition IEP or 504 Plan
School Resources

Classroom Curriculum

What’s HEALTH Got To Do with TRANSITION?

CURRICULUM

Links to Lesson Plans

Parent/Student Handouts
#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.
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 young adults with intellectual 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 health care or in financial management.

Many parents and caregivers are surprised to learn that when their child turns 18, they may not be able to direct or 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 benefits or 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 complication may be realized.

There are several levels of healthcare and financial decision-making assistance available to Floridians, ranging from informal "shaded" 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.centerforguardianadvocacy.org). For a full list of options for people with ID/DD, visit www.fssflorida.org/Stevens/guardian/a_main.htm.

Certainly, cost for legal services – which can exceed $3,000 for guardianship – is a concern for most families. However, income-eligible consumers may qualify for pro bono or reduced-fee services through Florida Legal Services, a statewide network of organizations that provide legal assistance based on need (http://floridalawhelp.org). The Center for Guardian Advocacy also uses a sliding fee scale. The Florida Bar operates a lawyer referral service at www.floridabar.org.

Families should plan to address decision-making alternatives prior to their child's 18th birthday. After age 18, the process becomes more complex and, often, more expensive.

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

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Contacts

- Hillsborough HATS
  Marybeth Dunn, MPH
  Coalition Coordinator
  marybeth@psrtampaBay.org
  (727) 272-5251

- Florida HATS
  Janet Hess, DrPH, MPH
  Florida HATS Project Director
  jhess@health.usf.edu
  (813) 259-8604