Preparing Teens for Transition to Adult Health Care:

10 Steps to Successful Health Care Transition

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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.

Definition

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 ongoing patient-centered adult care.
Agenda

- Why is health care transition important?
- What steps can you take to ensure successful transition?
- How can FloridaHATS and HillsboroughHATS help?
Why is health care transition important?

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

Institute of Medicine, 2007
“When we left pediatric care, it was as if someone flipped the switch and turned the lights off.”

- Parent of child with developmental disability
“It’s like taking 18 years to build a fine canoe and then riding it over a waterfall.”

- Parent of a child with special health care needs
What can happen?

- Without adequate support in moving from pediatric to adult care, youth may:
  - Experience loss/gaps in insurance
  - Have poor connections to the adult health care system
  - Have decreased adherence with medicine, self-care
  - Have increased ER visits, hospitalizations
  - Experience short term deterioration in health and worse long-term outcomes

Institute of Medicine, 2007; Boyle et al. 2001; Callahan et al. 2001; Betz 2003; Freyer et al. 2008; Tuchman et al. 2008), Watson 2000; Annunziato et al. 2007; Gurvitz et al. 2007; Dugueperoux et al. 2008; White 2002; Williams 2009.
Goals for transition

- Manage 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

Florida’s clearinghouse for HCT information

www.FloridaHATS.org
Florida Health and Transition Services

Welcome to the FloridaHATS Web site! FloridaHATS is a program of Florida Department of Health, Children’s Medical Services Managed Care Plan (CMS Plan). Our mission is 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. To learn more about our program, visit About Us.

Tool Box

Our health care transition tool box contains documents and links to a variety of local, state and national resources. Materials for youth, families and professionals are organized in these categories:

- For Health Care Practitioners
- Independent Living
- For Youth & Families
- Decision-Making & Guardianship
- Education & Training for Professionals
- Service Delivery & Models of Care
- Health Insurance & Financing
- Advocacy
- Secondary & Post-Secondary Education
- Juvenile Justice System
- Regional Coalitions
- HillsboroughHATS
- Northeast FloridaHATS
- PanhandleHATS
- South FloridaHATS

Some Resources

- Understanding Florida Medicaid Managed Care From Family Network on Disabilities (2016)
- My Health Care A classroom curriculum to improve health literacy, communication and self-advocacy skills

Some Materials for Youth and Families

- Just the Facts: The 411 on Health Insurance for Young Adults Ages 18-30 in Florida (2015)
- Transition 2 Go International Briefs On Florida Guardianship, Employment, Social Security, and

Some Tools for Providers

- Condition-Specific Tools for Subspecialists From the American College of Physicians, tools are now available for the following subspecialties: general internal medicine, pediatrics, neurology, mental health, orthopedics, and

Need Training?

- Health Care Transition Training for Health Care Professionals. This course is appropriate for all practitioners and support staff involved in the care of adolescents and young adults.
- Illinois Transition Care Project Offers
10 Steps to Successful Health Care Transition Care Transition
Begin preparing for transition even when young, such as starting a health summary and talking about health needs.
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.
Culture shock

**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
Self-management guides

www.floridahats.org/?page_id=616
Self-management videos

Short Videos with step-by-step instructions

www.floridahats.org/?page_id=616
#3: Create a health summary

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

http://flfcic.fmhi.usf.edu/program-areas/health.html

www.gottransition.org/resourceGet.cfm?id=227
#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.
**Sample Plan of Care**  
**Six Core Elements of Health Care Transition 2.0**

Instructions: This sample plan of care is a written document developed jointly with the transitioning youth to establish priorities and a course of action that integrates health and personal goals. Motivational interviewing and strength-based counseling are key approaches in developing a collaborative process and shared decision-making. Information from the transition readiness assessment can be used to guide the development of health goals. The plan of care should be dynamic and updated regularly and sent to the new adult provider as part of the transfer package along with the latest transition readiness assessment, medical summary and emergency care plan, and, if needed, a condition fact sheet and legal documents.

Name: ___________________________  
Date of Birth: ______________________

Primary Diagnosis: __________________  
Secondary Diagnosis: __________________

What matters most to you as you become an adult? How can learning more about your health condition and how to use health care support your goals?

<table>
<thead>
<tr>
<th>Prioritized Goals</th>
<th>Issues or Concerns</th>
<th>Actions</th>
<th>Person Responsible</th>
<th>Target Date</th>
<th>Date Complete</th>
</tr>
</thead>
</table>

Initial Date of Plan: ________________  
Last Updated: ________________  
Parent/Caregiver Signature: ________________

Clinician Signature: ________________  
Care Staff Contact: ________________  
Care Staff Phone: ________________

© Got Transition™ Center for Health Care Transition Improvement, 01/2014  
Got Transition™ is a program of The National Alliance to Advance Adolescent Health supported by U39MC25729 HHS/ACF/CFD  
www.gottransition.org

www.gottransition.org/resourceGet.cfm?id=226
#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!
Resources

Healthy Transitions Mobile App

http://flfcic.fmhi.usf.edu/docs/Parent_LowRes_English.pdf

www.aucd.org/template/news.cfm?news_id=11188&id=17
#6: Integrate HCT activities in the school setting, including 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
Educator Training

Health Care Transition in the School Setting: A Training Program for Educators provides special education teachers, transition specialists, administrators and support staff with the knowledge, skills and tools to facilitate improved health literacy, self-management, communication, and self-advocacy among students with disabilities and chronic health conditions. The course describes how health care transition is an integral component of successful transition to post-secondary adult life, and demonstrates how to integrate health-related goals and objectives into federally-mandated transition Individualized Education Plans, 504 Plans, and Individualized Health Care Plans.

Course Modules

The course is comprised of 10 sequential modules, lasting an average of 15-20 minutes each. Total time to complete the course is approximately 3 hours. A short description of the module and learning objectives are provided with the video links below. Before starting, please download the Course Toolkit, which provides links to the tools and resources used throughout the course.

1. Introduction (Handout)
2. Adolescent Development (Handout)
3. Working with the Health Care Community (Handout)
4. Health Insurance (Handout)
5. Legal & Financial Aspects of Transition (Handout)
6. Assessing Health Care Transition Readiness (Handout)
7. Health Skill Development (Handout)
8. Care Transfer (Handout)
9. Conclusion (Handout)
10. Practice Activities (Handout)

Script for full course

www.floridahats.org/secondary-post-secondary-education/
My Health Care: A classroom curriculum

The goal of My Health Care is to empower persons with intellectual or developmental disabilities (IDD) to better meet their own health and wellness needs through improved communication with providers, the use of adaptive tools, and development of self-advocacy skills. The project is funded by the Florida Developmental Disabilities Council, Inc. (FDDC) and was developed in partnership with the University of South Florida.

My Health Care is organized around the mnemonic “GLADD,” a teaching model developed at University of Florida’s Institute for Child Health Policy. GLADD serves as a reminder about important skills to use when communicating with health care providers and others. (Give Information—Listen—Ask questions—Decide—Do. Follow through on the action plan).

My Health Care activities within the GLADD model include:
- Being prepared with questions and issues to discuss at office visits
- Providing a health summary to the physician
- Being assertive when communicating and paying attention to body language
- Using rating scales and visual aids to communicate health issues
- Learning nonverbal skills providing feedback to the physician
- Utilizing caregivers to assist with communication
- Recording communication with physician to enhance information recall and comprehension
- Utilizing technology to improve health care communication and self-management

In addition to using GLADD to guide skill-building, learners are introduced to other fun and easy-to-remember mnemonics such as SLANT (Sit up-Lean in—Ask questions—Non-Technical use tone when talking to a provider), and Handy High F (Who—What—When—Where—Why: to use in describing a medical event or condition).

Health Literacy, Communication, and Self-Advocacy Instruction for Individuals with Intellectual or Developmental Disabilities

www.cpalms.org/project/my_health_care.aspx
#7: Know options for health insurance and public assistance programs in adulthood.
Health insurance after age 18

- Aging out of childhood health insurance plans can create gaps/loss in coverage
- Benefits in temporary jobs often limited, unavailable, or have high premiums
- Increased salary may lower/eliminate public benefits
- Limited benefits provided in adult Medicaid package
• Plan for change in insurance coverage
  - Medicaid
  - Parents’ plan
  - Employer-based
  - Marketplace plans
Transition 2 Go

in Florida

School to Work Transition
Vocational Rehabilitation

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

Transition planning for individuals who have disabilities and are about to enter the workforce should address an array of VR programs, including the School to Work Transition program. The School to Work Transition program specifically helps students ages 14-21 prepare for post-secondary education, training, and/or a job at a high school.

Any student with a disability may be eligible for the School to Work Transition program if that student receives special education services and a referral to VR as part of the student’s transition or IEP. Students who need VR should contact their school counselor. School counselors will make referrals to VR.

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

December 2012

Transition 2 Go

in Florida

Home and Community-Based Living Medicaid Waivers

Home and Community-Based Services (HCBS) Waivers are Medicaid programs that provide services to persons who would otherwise require institutional care in a hospital or nursing facility. Without waiver services being delivered in the community, some adults and young adults might not be able to live at home or receive needed support in the workplace.

Waivers provide specific services over and above those in the general Medicaid adult benefits package and are targeted to persons who demonstrate the need for a high level of community supports. Waivers are available on a first-come, first-served basis. Waiting lists for Florida Medicaid Waivers are also available.

There are currently 15 HCBS waivers in Florida. The largest one is for HCBS with developmental disabilities ages 3 and older, administered by the Agency for Persons with Disabilities (APD). APD offers a broad range of supports and services to assist people with developmental disabilities, defined in Florida as those who have autism, cerebral palsy, Down syndrome, intellectual disabilities, Prader-Willi syndrome, or specific forms of epilepsy. Services may include personal care assistance, companionship services, transportation, therapy, and other supports. Individuals are typically referred to APD through their local APD office.

For more information about the program and applying for services at one of APD’s 14 area offices, visit http://apd.florida.gov. Families should also visit the Florida Family Care website at www.healthyflorida.org.

Health care professionals can help assure that young people with disabilities, especially those with developmental disabilities, and their families are aware of Medicaid waiver programs as a potential source of services and supports, and provide required documentation as needed. Due to long waiting lists, it is important for families to apply early, even before services might be needed.

For full list of waiver programs and descriptions, see Florida Medicaid Summary of Services at http://www.floridahealth.gov/Apps/Medicaid/FFS/2013_Summary_of_Services_Final_120313.pdf

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

Issue no: 3

APD/Med Waiver

Supplemental Security Income: What Happens to My SSI When I Turn 18?

Tip Sheet 3

TRANITIONS RTC
April 2011

Can I keep my SSI?

• The answer is – it depends you need to re-apply.

• Social Security will review your case.

• Once you are not a child anymore, you will need medical evidence to prove that you are disabled as an adult.

• 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 will count up to $6,600 of earnings before deducting from your benefits.

• 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.

Can I work?

Are there ways to earn money without reducing my SSI check?

What if Social Security turns me down when I turn 18?

• 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 6 months afterward.

• Visit us online at http://flahs.m Peweed.gov/transitionsRTC

Voc Rehab

Fl State University

SBISS

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Voc Rehab

Fl State University

SBISS
#8: 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
- Are willing to take primary responsibility for care
- Provide developmentally appropriate services for low functioning young adults
- Accept Medicaid
By age 17

www.floridahats.org/?page_id=596
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.

Please help us keep the directory up-to-date! We encourage both consumers and providers to let us know about resources you think should be included. For instructions on how to add a service or recommend a program, please visit our directory submission page. To update an existing entry, first search for listing using the form below. Open the current listing, in upper right-hand corner, click on the “Update this listing” text link. Make corrections on form page then click submit. All information that is submitted will be verified prior to uploading to the directory.

**Search By: Categories AND/OR Keyword(s)**

- **City, State, County**
  - -- Any City --

- **County**
  - -- Any County --

- **Health Category**
  - -- Any Health Category --
  - Behavioral and Mental Health
  - Dental
  - Eating Disorders
  - Employment

- **Search by Keyword(s)**

- **Submit**
- **Reset**

www.floridahats.org/service-directory/search-service-directory
#9: 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.
Decision-Making

- Consider options, such as POA, supported decision-making, guardianship, guardian advocacy
- Explore long-term financial planning strategies, such as a special needs trust

www.floridahats.org/?page_id=614
#10: 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.
Free CE/CME for health care professionals

- Web-based cross-disciplinary training for professionals
  - 10 modules, 15-20 minutes each
  - Free CE/CME for physicians, nurses, social workers, dieticians, psychologists, mental health workers, respiratory therapists, dentists
  - CME/CE available through Gulfcoast AHEC at [www.aheceducation.com](http://www.aheceducation.com)
  - Modules also posted on [www.FloridaHATS.org](http://www.FloridaHATS.org)
  - Updated in summer 2017
HillsboroughHATS Regional Coalition

• Group of providers, families/youth, agencies, and other advocates, with CMS oversight
• Face-to-face and teleconference meetings
• Strategic Action Plan
  ○ Community events
  ○ School, social service linkages
  ○ Partner with hospitals, medical/nursing associations
  ○ Training, outreach Grand Rounds presentations
• See www.floridahats.org/hillsborough-hats
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