Preparing Students with Disabilities for Transition to Adult Health Care:

10 Steps to Successful Health Care Transition

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Agenda

- Why is it important?
- How are we doing?
- What can you do to facilitate successful transition?
- How can Florida HATS help?
Health Care Transition

**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+

**Health Care Transition (HCT)**
“... the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems.”
Blum, 1993

“... to maximize lifelong functioning and well-being for all youth, including those who have special health care needs and those who do not.”
AAP/ACP/AAAAF, 2011
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

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 vs. Florida
Outcome successfully achieved

2009-2010 National Survey of Children with Special Health Care Needs
Transition Preparation and the School Setting

- Skills used in transition are similar to other expectations of independence
- Practical and comfortable learning environment
- Opportunity for synergy with transition IEP process
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
- **Expands Medicaid eligibility to all legal residents up to 133% FPL**
- Increase Medicaid reimbursements for some PCPs to Medicare level
- Creates state-based health insurance Exchanges to provide more private options
- 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
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 tree 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 (English 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.

Related Service Directories in Florida:
- Project 10’s Florida District Resource Directory
- Florida Community Health Centers
- Agency for Persons with Disabilities Resource Directory
- Family Network on Disabilities
- Healthy Athletes Resource Directory
- Find-a-Ride Florida Resource Directory
- CMS Provider Search
- 2-1-1 Helplines in Florida
- WaiverProvider.Com
- Where To Find Help in Florida
- Adult Primary Care Providers in Hillsborough County

Search By: Categories AND/OR Keyword(s)

City, State, County:  [Select] Any City

County:  [Select] Any County

Health Category:  [Select] Any Health Category

Search by Keyword(s):  

Submit Query  Reset
Secondary & Post-Secondary Education

Secondary Education

- 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!
- Embedding Health Care Transition Outcomes in IEPs (Waismann Center, University of Wisconsin)
- Advocating for Yourself in School (tips for middle and high school students)
- Preparing for IEP Meetings (10 steps for parents to prepare for IEP meetings)
- FL School District/Social Service Agency Contacts (contacts by school district for foster care liaisons, children's legal services, community-based care, and DCF regional directors)
- Curriculum for High School Students in Special Education (updated 2009, USF). A comprehensive 40-hour classroom curriculum that promotes health literacy, self-determination, and health care management skill-building; includes a detailed Teacher's Guide. Findings from the intervention are reported in this article in the Journal of Pediatric Psychology.
- Healthy Transitions (lesson plans, videos, and other tools for students with intellectual disabilities)
- Transition Planning Guide (from the Florida Department of Education/Project 10)
- Learning About Health Insurance (Grade 5-12 Curriculum from the University of Maine)
- My Health, My Choice, My Responsibility (from the Westchester Institute for Human Development)
- Staying Safe at Work (brochure about occupational health curriculum from University of CA, Berkeley)
- Sexuality Across the Lifespan (FDCC, Univ. of Albany)
- Spina Bifida Overview for Teachers (Fact sheet from the Spina Bifida Association)
- Sample Section 504 Plan for Diabetes (from American Diabetes Association)
- GEMS (tools for schools concerning students with genetic conditions)
- Family Network on Disabilities (multiple programs for families of children/students with disabilities)

Post-Secondary Education

- Florida Consortium on Postsecondary Education and Intellectual Disabilities (existing programs in Florida for students with intellectual disabilities)
- Going to College (for students with disabilities, from Virginia Commonwealth University)
- College and Disability Services (video from Pacer Center)
- Universal Design (AHEAD)
- College Students with Chronic Medical Conditions (AHEAD)
- College Students with ADHD (AHEAD)
Guardianship and Alternatives for Decision-Making Support

For a person-aged adult who has intellectual disabilities, his or her health care transition often raises questions for health care providers and families about guardianship. This brief provides a high-level look at guardianship and other decision-making supports as well as resources that will provide more in-depth information.

**Guardianship Issues**

**Reaching the age of 30 — Opportunities and Challenges for Young Adults with Intellectual Disabilities**

Reaching the age of majority (30 years) in most states and jurisdictions means, under state law, an individual is no longer a minor. As such, the person has the right and responsibility to make some legal choices that adults make. For many young adults with intellectual disabilities, this may be an exciting opportunity for increased independence. However, they may also be fairly concerned about how to best support their self-determination in making life decisions such as for health care or in financial management.

This brief provides a broad outline of decision-making support options, such as informal and legal, that may assist young adults with intellectual disabilities. States and jurisdictions may have different laws and options. Each state defines the categories and rules for guardianship in its laws. It is important to know all of the options before deciding which one to pursue since every young person has a unique situation and individual needs for support.

**Decision-Making — A Skill that Requires Practice and a Variety of Experiences**

Decision-making is learned skill. Children and youth who have support and experience making choices every day, whether it be choosing which song to play, will approach adulthood having exercised this skill. However, ongoing decision-making experiences make the transition to adulthood smoother. When young adults with intellectual disabilities are given the opportunity to make decisions or to participate in a shared decision-making process, this lack of skill building may lead to perceived "incompetency" either by the family or by the young adult him/herself.

Despite having opportunities for decision-making only in the not, not all young adults with intellectual disability are able to make all decisions, especially those with

**Guardianship**

**Florida 2011**

**Got Insurance? How to Get It, Keep It and Use It!**

**Just the Facts: The 411 on Health Insurance for Young Adults Ages 18-30 in Florida**

Including Those with Chronic Health Conditions or Disabilities

Version 1.2, updated July 2011
Transition 2 Go

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 at age 14. Students who receive special education services, schools often take the lead in VR referral to VR as part of the student’s transition Individualized Education Plan. However, having an IEP is not a VR eligibility requirement. Health care providers can help assure that all young people with disabilities and their families are aware of VR as a potential source of services and supports, and facilitate access by providing appropriate VR referrals as needed.

Students who may benefit from VR services should apply at least 2 years before leaving high school, e.g., apply at age 16-17 leaving high school at age 18. They also assist students with community work experience while they are still in high school. Applications can be downloaded at http://rehabworks.org/docs/vrapp.pdf.

VR referrals can be made by anyone by contacting the local VR office or by www.rehabworks.org (click on VR Office Directory). To learn more about the School to Work Transition program, visit www.rehabworks.org/docs/SchoolToWorkTrans.

For more information about this topic, contact Janet Hess at jhess@health.uwf.edu or (813) 258-8604.

Transition 2 Go

Home and Community-Based Living Medicaid Waivers

Home and Community-Based Services (HCBS) Waivers are Medicaid programs that provide services in the home for persons who would otherwise require institutional care in a hospital or nursing facility. Without waiver services being delivered in the community, some adolescents and young adults might not be able to live at home or receive needed supports 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 care. Enrollment is typically capped; once enrollment reaches a specified number or dollar threshold, waiting lists are created. The waiting lists for Florida Medicaid Waivers are often years.

There are currently 15 HCBS waivers in Florida. The largest one is for individuals 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 persons with developmental disabilities, defined in Florida as those who have autism, cerebral palsy, Down syndrome, intellectual disabilities, Prader-Willi syndrome and certain forms of spina bifida. Services may include personal care assistance, companion services, transportation, therapy, behavioral support, skilled nursing, durable medical equipment, and supported employment services. All services require determination of medical necessity. For more information about the program and applying for services at one of APD’s 14 area offices, visit http://apdcares.org. Families should also visit the Florida Agency for Persons with Disabilities web site at www.flapd.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://flhcc.state.fl.us/medicaid/publications/2012-2013-Summary-of-Services-Eng.pdf.
Transition for Students with Disabilities

How to Get What You Need

You should always be able to have the accommodations you need in school for your exam or exam day. Sometimes it also takes extra effort to get what you need. Having a disability doesn’t mean you can’t do as well as the other students in school. You have the same high as others to succeed. By law, every school has a process or a set way to help students and others about what you need. Sometimes this is done through a formal plan called an Individual Educational Plan (IEP) or a 504 plan.

Step 1: Evaluate what you need.

Sit down with your parents and decide what accommodations you need based on your disability. Be as specific as possible. Know what you need. People with different disabilities need different things. Using fewer accommodations while in school will help your prepare for post-secondary education or training, where fewer accommodations are allowed.

Step 2: Find a helpful resource at school.

This could be a teacher, vice-principal, transition specialist, or someone who is willing to work with you and make sure you get what you need. Add other kids who get accommodations at school what works for them, or talk to take the principal about what is available. Once you find a helpful resource, have a meeting with that person and see what they can do to help you advocate for yourself.

Step 3: Talk to your teachers.

Try to have a meeting that includes all your teachers, your parents, transition specialist, and other people who help you. Make sure to share the things that work for you. Teachers have overall authority in the classroom, so it’s important that they understand your needs. If your teachers don’t know, ask for a letter. If your teachers don’t know, go to your teachers and tell them that you can contact your parents with any questions. If a teacher is unwilling to work with you, talk to your principal or Director of Exceptional Student Education (ESSE) about the problem. Teachers must be fair to all students.

Step 4: Have a follow-up meeting.

Several times during the school year, you should try to see your transition specialist or another resource staff, and let them know what’s going on. Halfway through the year, you should have a meeting with your parents and resource staff, and try to have one teacher present to talk about what is working for you and what isn’t.

Other forms of advocacy for you and getting what you need:

- Know about your disability so you can explain its strengths or weaknesses.
- Your health information is confidential. It’s your decision about how much you want to share.
- Teachers and other staff are not allowed to discuss your personal information unless it is necessary for their job.
- Ask for a statement that someone is having difficulty understanding your disability, or you can be excused from the test.
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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 graduation from pediatrics and transition to adult healthcare.

Components of Module 1
- Transitioning Youth: "Transitions from Pediatrics to Adult Health Care"
- What is Health Care Transition?
- How can transitions be improved?
- "Real Story" 
- Policies and practices of Health Care Providers and Facilities
- Transitioning youth & young adults with different cultures and health care histories
- Transition to Education
- Transitions in Vocational Rehabilitation
- Legal Rights of Individuals with Disabilities

Components of Module 2
- College and Beyond
- Developmental Model of Health Care and Childhood-Adulthood Relationships
- Young Adult Readiness to Transition
- "Real Story"
- "Real Story"
- Perspectives from Youth and Young Adults for Transitioning Youth
- Transitioning Youth and Young Adults: A Focus on Chronic and Healthcare Providers
- Transition Resources of the Institute for Child Health Policy, University of Florida

Accreditation

The four-hour-long Health Care Transition Training Program is broken down into two three-hour modules. The accreditation statements below apply to each module for a total of 3.0 contact hours.

Physicians: This activity has been planned and implemented in accordance with the Essential Areas and Policies of The Accreditation Council for Continuing Medical Education through the joint sponsorship of the Florida AHEC Network, the University of Florida, the University of South Florida, the Florida Department of Education, and the Florida Department of Health. This program meets the requirements for up to 3.0 total contact hours for two modules.

Nurses, Advanced Practice Nurses, Social Workers: This activity qualifies for 3.0 contact hours for continuing education provided by the Florida AHEC Network.

Other Health Professionals: This activity qualifies for 3.0 contact hours for continuing education provided by the Florida AHEC Network.

www.aheceducation.com
Role of School Nurses and Special Education Personnel

- Provide linkage between pediatric and adult health systems
- Help students/families to understand, identify, and access adult services and resources
- Encourage self-management activities and skills
- Collaboration with community-based providers and other school staff on HCT issues
- Proactive consideration of health-related factors in development of transition IEPs
- Support for optimal functioning, independence, and self-determination
Contacts

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www.FloridaHATS.org