Transition to Adult Care: Resources for Pediatricians

Janet Hess, DrPH, MPH

September 18, 2014
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.
The AAP, AAFP, and ACP recommend transition planning as a standard of care for all adolescents

Population Model

Chronic Condition Care Coordination

Enhanced Planning

Transition Plan Preparation Assessment Information & Referral

YSHCN

All Youth

Pediatric Care System Adult Care System
1. Do you have a practice policy for transitioning patients to an adult model of care?

2. What steps do you take to prepare adolescents and their families for the change?
Florida’s clearinghouse for health care transition information at www.FloridaHATS.org
Transition Toolkit

- Visit [www.jaxhats.ufl.edu](http://www.jaxhats.ufl.edu) or [www.FloridaHATS.org](http://www.FloridaHATS.org)

- Account Set Up
  - Email address

- Which position best describes you?
  - Medical Provider
  - Youth and/or Caregiver
  - Case Manager
  - Teacher
Medical Provider

Question 1
Do you have a Transition Policy established in your practice or facility?  ☐ Yes  ☐ No

Question 2
Do you have a checklist or method that helps patients through the transition process?  ☐ Yes  ☐ No

Question 3
Do you currently provide your patients with a portable health summary after each visit?  ☐ Yes  ☐ No

Question 4
Do you currently use a Transition Readiness Assessment Tool?  ☐ Yes  ☐ No

Question 5
What are the age range of your patients?
☐ 12-14
☐ 15-17
☐ 18 and older

Question 6
Do you maintain a Transition registry to track and monitor patients through transition?  ☐ Yes  ☐ No

Question 7
For Pediatric providers and practices: Do you use a transfer letter?  ☐ Yes  ☐ No  ☐ N/A

Question 8
For Pediatric providers and practices transferring youth out: Do you have a way to elicit patient feedback after transfer?
☐ Yes  ☐ No  ☐ N/A
Policy for Transition to Adult Care

USF models its transition policy upon the guidelines provided by the American Academy of Pediatrics' joint clinical report on transition and by Bright Futures. We believe that a smooth transition from adolescence to young adulthood includes the explicit transition from a pediatric to an adult health care model and the eventual transfer of health care to adult providers. This process requires joint planning, preparation, and implementation to begin by age 18. At age 14, most youth in our practice will transition to an adult model of care with modifications as needed for youth with intellectual disabilities though the actual transfer of care to adult providers may take place later. We honor the preferences of the youth and family regarding the eventual transfer of care to an adult primary care medical home, but we generally expect this to occur at sometime between 18 and 21 years of age.

Our approach to the care of young adults age 18 and older meets HIPAA and state privacy and consent requirements making the young adult the sole decision-maker about care and about the sharing of personal health information. Exceptions to this approach require legal authority through the signed consent of the young adult, legally valid custodial care or power of attorney documentation, or an adjudicated guardianship arrangement.
<table>
<thead>
<tr>
<th>Age Group</th>
<th>Task</th>
<th>Date Discussed</th>
<th>Completed</th>
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<tbody>
<tr>
<td>Ages 12-14</td>
<td>Develop knowledge of your health care needs</td>
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<td></td>
<td>Youth should be able to:</td>
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<tr>
<td></td>
<td>□ [ ] describe medical condition(s)</td>
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<td></td>
<td>□ [ ] name medication(s)</td>
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<td></td>
<td>□ [ ] manage routine medical tasks</td>
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<td></td>
<td>Explore appropriate work and volunteer opportunities</td>
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<td></td>
<td>Answer questions during a health care visit</td>
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<td></td>
<td>If eligible, sign up for Agency for Persons with Disabilities Med Waiver</td>
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<td></td>
<td>Continue self-advocacy skills, especially with health care providers and teachers</td>
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<tr>
<td>Ages 15-17</td>
<td>Take responsibility for making medical appointments and getting prescriptions refilled</td>
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<td></td>
<td>Talk to medical providers during visits about age-appropriate information regarding physical, emotional, and sexual development</td>
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<td></td>
<td>Begin thinking and talking about transition from pediatric to adult health care providers</td>
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<td></td>
<td>Discuss pediatrician’s discharge age and plan for transition and transfer to adult care accordingly</td>
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<td></td>
<td>Keep a health record, including all medical paperwork</td>
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<td></td>
<td>Youth spend the majority of health care visits alone with the doctor</td>
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<td></td>
<td>Check in annually with APD regarding the waiver waitlist status</td>
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<tr>
<td>Prior to 18th Birthday</td>
<td>Finalize adult health care coverage</td>
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<td></td>
<td>Resubmit Medicaid benefits</td>
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<td></td>
<td>Resubmit for SSI Benefits (17 years and 11 months)</td>
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<td></td>
<td>Make decisions about Power of Attorney or other Guardianship options</td>
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<tr>
<td>Age 16+</td>
<td>Transfer medical care from pediatric providers to adult providers</td>
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<tr>
<td></td>
<td>Resubmit Medicaid Benefits</td>
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<td></td>
<td>Contact Vocational Rehabilitation to explore vocational assistance</td>
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<td></td>
<td>Explore living arrangements, education, and employment opportunities</td>
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<td></td>
<td>Make decisions regarding Power of Attorney or Guardianship</td>
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<td></td>
<td>Check in annually with APD regarding waiver waitlist status</td>
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<td>Transfer medications to local pharmacy (if moving or going away to school)</td>
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<td></td>
<td>If going to college, learn about health care coverage and health services provided on campus</td>
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</table>
3. Do you currently provide your patients with a portable health summary after each visit? No
Do you currently use a Transition Readiness Assessment Tool? No

**Transition Readiness Assessment Questionnaire 5.0**

*Directions: Please check the box that best describes your skill level in the following areas that are important for transition to adult health care. There is no right or wrong answer and your answers will remain confidential and private.*

<table>
<thead>
<tr>
<th>Skill Area</th>
<th>No, I do not know how</th>
<th>No, but I want to learn</th>
<th>Yes, I am learning to do this</th>
<th>Yes, I started doing this</th>
<th>Yes, I always do this when I need to</th>
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<tbody>
<tr>
<td>Managing Medications</td>
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<tr>
<td>1. Do you fill a prescription if you need to?</td>
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<td>2. Do you know what to do if you are having a bad reaction to your medications?</td>
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<td>3. Do you take medications correctly and on your own?</td>
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<td>4. Do you reorder medications before they run out?</td>
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<td>Appointment Keeping</td>
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<td>5. Do you call the doctor's office to make an appointment?</td>
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<td>6. Do you follow-up on any referral for tests or check-ups or labs?</td>
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<td>7. Do you arrange for rides to medical appointments?</td>
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<td>8. Do you call the doctor about unusual changes in your health (For example: Allergic reactions)?</td>
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<td>9. Do you apply for health insurance if you lose your current coverage?</td>
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<td>10. Do you know what your health insurance covers?</td>
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<td>11. Do you manage your money &amp; budget household expenses (For example: use checking/debit card)?</td>
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<tr>
<td>Tracking Health Issues</td>
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<td>12. Do you fill out the medical history form, including a list of your allergies?</td>
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<td>13. Do you keep a calendar or list of medical and other appointments?</td>
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<td>14. Do you make a list of questions before the doctor's visit?</td>
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<td>Talking with Providers</td>
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<td>15. Do you get financial help with school or work?</td>
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<td>Managing Daily Activities</td>
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<td>16. Do you help plan or prepare meal/Food?</td>
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<td>17. Do you keep home room clean or clean-up after meals?</td>
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<td>18. Do you use neighborhood stores and services (For example: Grocery stores and pharmacy stores)?</td>
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<table>
<thead>
<tr>
<th>#</th>
<th>Question</th>
<th>Answer</th>
<th>Resources</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Do you have a Transition Policy established in your practice or facility?</td>
<td>No</td>
<td>Transition Policy</td>
</tr>
<tr>
<td>2</td>
<td>Do you have a checklist or method that helps patients through the transition process?</td>
<td>No</td>
<td>Transition Checklist for Providers</td>
</tr>
<tr>
<td>3</td>
<td>Do you currently provide your patients with a portable health summary after each visit?</td>
<td>No</td>
<td>H.I. Doc.</td>
</tr>
<tr>
<td>4</td>
<td>Do you currently use a Transition Readiness Assessment Tool?</td>
<td>No</td>
<td>Transition Readiness Assessment Tool</td>
</tr>
<tr>
<td>5</td>
<td>Age range of patients?</td>
<td>18 and older</td>
<td>10 Steps to Successful Transition I</td>
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<td>Envisioning My Future: English</td>
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<td>Health and Transition Checklist for Ages 18 and older</td>
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<td>SSI Info</td>
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<td>SSI Tip Sheet</td>
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<td>Medicaid Info and Insurance Guide</td>
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<td>Information on Guardianship Options</td>
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<td>For additional resources, visit: <a href="http://www.floridahats.org">www.floridahats.org</a> and <a href="http://www.gottransition.org">www.gottransition.org</a>.</td>
</tr>
<tr>
<td>6</td>
<td>Do you maintain a Transition registry to track and monitor patients through transition?</td>
<td>No</td>
<td>Transition Registry</td>
</tr>
<tr>
<td>7</td>
<td>For Pediatric providers and practices: Do you use a transfer letter?</td>
<td>No</td>
<td>Transfer Letter</td>
</tr>
<tr>
<td>8</td>
<td>For Pediatric providers and practices transferring youth out: Do you have a way to solicit patient feedback after transfer?</td>
<td>No</td>
<td>Feedback Survey - Youth</td>
</tr>
</tbody>
</table>
Case Manager

Transition Toolkit

Here are some commonly used resources for youth in transition.

- **Medicaid Information**
  - This includes eligibility information, tips on how and when to apply, and useful contact information.
    - English
      - What is Medicaid and How to Apply
      - Who to Contact at Medicaid
    - Español
      - Qué es Medicaid y cómo aplicar
      - Quién contactar en Medicaid

- **Insurance Information**

- **Self-Advocacy Tools**
  - Use these tools for empowerment and to promote independence with your youth.
    - Self-Advocacy: Find the Captain In You!
    - Advocating for Yourself in Middle School and High School
    - GLADD Tool

- **SSI Information**
  - Information about changes to SSI when someone turns 18.
    - SSI Tip Sheet
    - Apply for SSI

- **Health Care Provider**
  - JaxHATS is a local resource in NE Florida; a health and transition clinic for youth with special health care needs in transition.
  - FloridaHATS
    - A clearinghouse for information and resources regarding health care transition across the state. 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.

- **Dental Provider**
  - UF Health Tacachale Dental Clinic provides dental services to adults with developmental disabilities in NE Florida.
  - Medicaid Provider Service Network - See Page 32
    - A list of dental providers who accept Medicaid for youth. Dental services are generally not covered for adults ages 21 and older who have Medicaid and Medicare.
Teacher

Transition Toolkit

Here are some resources related to health care transition that can be adapted and utilized in the classroom.

- "What's Health Got To Do with Transition?" Curriculum (PDF)

- Project 10: Transition Education Network
  - The mission of Project 10: Transition Education Network, hereinafter referred to as "Project 10," is to assist Florida school districts and relevant stakeholders in building capacity to provide secondary transition services to students with disabilities in order to improve their academic success and post-school outcomes.

- Health Care Transition Preparation for YSHCN in Florida (PDF)
  - This transition guide was developed to assist all Youth with Special Health Care Needs in Florida prepare for transition.

- Healthy Transitions
  - Lesson plans for students with ID/DD

- Other Secondary/Post Secondary Resources
Youth and Caregiver

Transition Toolkit

These tools and resources will be most helpful for youth transitioning from pediatric to adult health care. Many changes are happening all at once and these resources will help you make appropriate decisions when it comes to your health care.

- **SSI Information**
  - Information about changes to SSI when someone turns 18.
    - SSI Tip Sheet (PDF)
    - Apply for SSI

- **Health Care Provider**
  - JaxHATS is a local resource in NE Florida, a health and transition clinic for youth with special health care needs in transition.
  - FloridaHATS
    - A clearinghouse for information and resources regarding health care transition across the state. 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.

- **Guardianship Information**
  - Powers of Attorney explained (PDF)
  - Find out the Guardianship options (PDF)
  - (Right to Decide) Health Care Advanced Directives

- **Self-Advocacy**
  - Know how to advocate for yourself and your health care needs.
    - Find the captain in you...watch this informative and empowering video as two teens explore what Self-Advocacy really means.
    - Advocating for Yourself In Middle School and High School (PDF)
    - GLADD Tool
      - Learn about the GLADD approach to talking with health care professionals.
        - G=Give information L=Listen A=Ask D=Decide D=Do

- **Dental**
  - Medicaid only covers some dental services up until the age of 21. After 21, you may apply for insurance through an exchange. Individual dental plans start as low as $10.00/month. Just be sure to check out the network and be aware of the services needed and services covered in NE Florida.
  - UF Health Tacachale Dental Clinic provides dental services to adults with developmental disabilities.

- **Health Insurance**
  - Know what your insurance covers, when it may expire, and how to apply for coverage.
  - Medicaid
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
Educational Materials

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

Visit www.FloridaHATS.org to view in large print
Para español, visite nuestro sitio web.
Pou kreyòl, spoifie vi wון ay Embrèl nay

Version 1.3, updated July 2011
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 all teens and young adults, including those 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. **If you have an Individualized Education Plan (IEP) or 504 Plan, include health care self-management activities in the plan.** Consider self-determination and advocacy skills, understanding personal health conditions and needs, and knowing how to access health care services.

7. **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.

8. **Find adult providers.** If still in the care of pediatric providers, ask them to help you identify and transfer to a primary care physician and specialists (including mental health professionals) who work with adults. Transfer of care typically occurs between ages 18 and 21.

9. **Know about legal rights and responsibilities that start at age 18!** Learn about community services and supports for adults.

10. **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.

Visit www.FloridaHATS.org to find resources and services.
Self-Advocacy Guides

SINCE YOU’RE NOT A KID ANYMORE
it's time to be more in charge of your health

NOW that you're in High School...
it’s time to be more in charge of your health

WHEN you're 18
you are in charge of your health

Health Care Transition Guide for Teens in Middle School
Health Care Transition Guide for Teens in High School
Health Care Transition Guide for Young Adults
Self-Management Videos

9 short videos with step-by-step instructions

Bringing Medications to Your Medical Appointment
This video demonstrates how you can actively participate in the proper management of your health care by bringing all of your medications to every medical appointment.

View Video

JaxHATS Health Care Notebook
Learn how to organize and prioritize all of your health care information.

View Video

Paperwork at the Sign-in Desk
This video shows what type of paperwork you can expect to see when you register for your medical appointment.

View Video

Planning Your Visit
This video shows you the tools you will need to prepare for your medical appointment. Planning ahead will help you have a productive meeting with your providers.

View Video

Role of Aides at Medical Appointments
Learn about the role of an aide or companion at a medical appointment. The role of the aide should always be clarified at the beginning of the appointment.
Transition 2 Go

Health Insurance

Florida Health

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 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 find a job after leaving high school.

Any student with a disability may be eligible for VR services starting at age 16. Florida students receive special education services, schools often take the lead in referring students to VR as part of the student’s transition Individualized Education Plan (IEP). However, having an IEP is not a VR eligibility requirement. Health care professionals can help assure that all young people with disabilities and their families are aware VR as a potential source of services and supports, and facilitate access by making 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 if leaving high school at age 18. VR will also assist students with community work experience while they are still in high school. Applications can be downloaded at http://vrdata.florida.gov or more information contact Janet Hess at jhess@health.state.fl.us.

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

Home and Community-Based 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. Waivers provide for services to be delivered in the community, some adults might not be able to live in full support in the workplace.

Waveres provide specific services to general Medicaid adult benefits to promote the health and independence of people with developmental disabilities. Down syndrome, cerebral palsy, and Down syndrome services. Transportation, therapy, equipment, and support are medically necessary.

Health care professionals can make sure these developemental disabilities at a potential source of services and supports, and facilitate access by making referrals as needed.

For full list of waivers and services, call 1-800-963-5437.

For more information, contact Janet Hess at jhess@health.state.fl.us.

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 you will make these choices, therefore having a guardian is necessary.

There are several levels of healthcare and financial decision-making available as described by Florida’s residents,—including “guardian advocacy” and “guardian for an adult.”

Visit www.dcfstatefl.gov/guardianship/guardian_adult.html. For all full list of options for individuals with intellectual and development disabilities, please call 1-800-963-5437.

For more information, contact Janet Hess at jhess@health.state.fl.us or (813) 259-8604.
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
- Mental Health Access Line/CLEAR
- 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:  -- Any City --
County:  -- Any County --
Health Category:  -- Any Health Category --
Search by Keyword(s):  

[Submit Query] [Reset]
Training for Health Care Professionals

- Web-based, video format
- Recently updated with current evidence-based materials
- 10 modules
  - 15-20 minutes each; 3 hours total
  - Posted on FLHATS web site
- Free CME/CE (4 contact hrs) through Florida Area Health Education Center, www.aheceducation.com
Transition to Adult Care
Are YOU Prepared?

Does your practice have a policy for transitioning patients to an adult model of care?
What steps do you take to prepare adolescents and their families for the change?

The American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians recommend transition planning as a standard of care for all adolescents. Health Care Transition Training for Health Care Professionals will equip you with the knowledge and tools you need to facilitate smooth transition for every patient, including those with special health care needs.

This new course release from FloridaHATS includes evidence-based materials such as the "Six Core Elements of Health Care Transition 2.0" from Got Transition, the national Center for Health Care Transition Improvement. You will learn about developmental, social, legal, and financial considerations in planning for transition, using interactive tools and a Florida-specific planning algorithm to connect to local services and resources.

Health Care Transition Training for Health Care Professionals is composed of 10 sequential modules, each lasting about 15 minutes. You can link to the modules below or go to www.FloridaHATS.org. For CME/CE credit, visit www.aheceducation.com. Quality improvement methods, videos, and a downloadable Course Toolkit are used throughout these sessions:

1. Introduction
2. Adolescent Development
3. Working with Caregivers
4. Assessing Transition Readiness
5. Patient Skill Development
7. Insurance
8. Working with Adult Medicine
9. Care Transfer
10. Conclusion

Hear from young people about their health care transition experiences and what they think is important.

FloridaHATS offers many additional web-based resources for both practitioners and consumers, including a searchable Health Services Directory for Young Adults and interactive Transition Toolkits.

For more information, contact Janet Heris, DrPH, MPH, at the University of South Florida, jheris@health.usf.edu or (813) 259-8604.
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