Health Care Transition
Florida Association of Children’s Hospitals

David Wood, MD, MPH
October 3, 2013
www.jaxhats.ufl.edu
First the good news...

90% of Seriously Ill Children become adults
The bad news: They have to go through this to get there!
Sickle Cell Disease

Changing Epidemiology of Diseases Arising in Childhood

- **Congenital Heart Disease**
  - >1,000,000 adults in the U.S. have CHD
    - 419,000 with moderate to severe complexity
    - At risk for re-operation, premature mortality
  - More adults than children

- **Cerebral Palsy**
  - In US ~800,000 people have CP
  - >400,000 are adults

*United Cerebral Palsy website (www.ucp.org/ucp_generaldoc.cfm/1/9/37/37-37/447)*
Why is HCT Important?

Without support during transition youth may:

- Lose of insurance
- Poor connection to the adult health care system
- Have decreased adherence with medicine, self-care
- 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.
“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.”

--Jerry Bridgham, 2013
Transfer of Care
Discrete event, physical transfer from a pediatric to an adult provider; should occur between ages 18-21+

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+

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

“The goal of a planned health care transition is 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/AAFP, 2011
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

Florida Health Care Transition Services
Task Force for Youth and Young Adults
with Disabilities

Report and Recommendations
Implementation of Senate Bill 988

Ensuring Successful Transition
from Pediatric to Adult Health Care

Joseph J. Chiaro, M.D., FAAP, Chair
Health Care Transition Services
Task Force
January 1, 2009
Population Model of HCT

- Medical Home & Care Coordination
- Assessment and Coordination
- Information & Referral

Increasing complexity of YSHCN

Pediatric Care System

Adult Care System
Estimates of Need for Transition Services

Florida
- 1.7 M young adults 18-24
- 85,000 Youth with significant physical or mental health care conditions

Northcentral Region Florida
- 257,000 young adults 18-24 years of age
- ~12,500 Youth with significant physical or mental health care conditions
## Need for Services—SSI

**Enrollment Ages 18-26**

<table>
<thead>
<tr>
<th>Region of Florida</th>
<th>Number of Young Adults on SSI</th>
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</thead>
<tbody>
<tr>
<td>Northwest</td>
<td>2,342</td>
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<tr>
<td>Big Bend</td>
<td>1,325</td>
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<tr>
<td>North Central</td>
<td>5,840</td>
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<tr>
<td>Tampa Bay</td>
<td>4,465</td>
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<tr>
<td>Central Florida</td>
<td>2,870</td>
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<tr>
<td>Southwest</td>
<td>2,456</td>
</tr>
<tr>
<td>Southeast</td>
<td>3,190</td>
</tr>
<tr>
<td>South Florida</td>
<td>4,223</td>
</tr>
</tbody>
</table>
How Are We Doing?

- National Survey of Children with Special Health Care Needs (every 4 years)
  - State and National Level Reporting

- 4 questions — anticipatory guidance for YSHCN ages 12-17 about:
  - Changing health needs in adulthood
  - Transition to adult health provider
  - Insurance needs into adulthood
  - Youth encouraged to take increased responsibility for care

- State Level — 37% (national 40%)
## Transition Support Services Offered to Adolescents with Special Health Care Needs

<table>
<thead>
<tr>
<th>Transition Services</th>
<th>For Nearly All or Most (%)</th>
<th>For Some (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assist with referral to specific family or internal medicine physicians</td>
<td>47</td>
<td>33</td>
</tr>
<tr>
<td>Assist with establishing referral to specific adult specialists</td>
<td>45</td>
<td>32</td>
</tr>
<tr>
<td>Discuss consent and confidentiality issues prior to age 18</td>
<td>33</td>
<td>27</td>
</tr>
<tr>
<td>Assist with medical documentation for program eligibility (e.g.,</td>
<td>32</td>
<td>34</td>
</tr>
<tr>
<td>Supplemental Security Income, vocational rehabilitation, college)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Discuss assent to care issues prior to age 18</td>
<td>31</td>
<td>27</td>
</tr>
<tr>
<td>Assist in creating a portable medical summary</td>
<td>27</td>
<td>26</td>
</tr>
<tr>
<td>Support family or internal medicine physicians with education and consultation</td>
<td>23</td>
<td>30</td>
</tr>
<tr>
<td>Assist with identifying options to maintain health care insurance after age 18</td>
<td>19</td>
<td>22</td>
</tr>
<tr>
<td>Create an individualized health care transition plan</td>
<td>12</td>
<td>26</td>
</tr>
<tr>
<td>Provide adolescents/parents with an educational packet or handouts</td>
<td>11</td>
<td>14</td>
</tr>
</tbody>
</table>

*Source: AAP Periodic Survey of Fellows #71, 2008*
FLORIDA CHILDREN’S HOSPITALS SURVEY RESULTS
Transition Programs

Does your hospital have an age limit?
- Yes (10)
- No (3)

Does your hospitals have a HCT program?
- Yes (5)
- No (5)
HCT Program Descriptions

- Most common specialties involved
  - Cardiology (3)
  - CF (3)
  - Sickle Cell (4)
  - IDD/CP (3)
  - Cancer Survivor (2)

- Extension of Complex Care Clinic (4)
  - Medical Home Model

- Transition problems identified by in-patient services
Departmental Responsibility

- Nursing—2
- Social Work—3
- Individual Specialty Programs (5)
- Others
  - CMS
  - Primary Care/Medical Home
Outreach

Transition Preparation Outreach and Education

- Pediatric Providers (3)
- Families (3)
- Inpatient services education (3)
- Outpatient clinic for medical/socially complex (2)

Outreach to and Recruitment of adult providers (4)
Discussions with adult systems

- Discussions with Adult Systems
  - 8 Hospitals
  - Variable response; specialty oriented

- Interest by adult system
  - Cost saving program (3)
  - Revenue losing (3)
  - Quality of Care (5)

- ACO? Only 1 yes
Planning/Development of HCT Programs

7 Hospitals Actively Planning
- Planning process is quite diverse with leadership from nursing, MD champions
- One hospitals starting with Adult Medical Homes (Baptist)
- Medical Home/Primary Care Programs
  - Wolfson, Holtz, St. Joseph’s, Joe DiMaggio
- Complex Care Clinics
  - Florida Hospital, Wolfson, UFH Shands
- In patient Consultation
  - Miami, Joe DiMaggio
- Care coordination
  - Wolfson, Holtz, Miami
HEALTH CARE TRANSITION PROGRAMS IN OTHER CHILDREN’S HOSPITALS
Martha Eliot Health Center

Transition Medicine

At Martha Eliot Health Center, our physicians are leaders in bridging the gap between pediatrics and adult medicine. Patients in our program are being followed for a variety of conditions, including congenital heart disease, autism, sickle cell disease, Type 1 diabetes, Down Syndrome and cerebral palsy. Our goal is to make the transition from pediatric to adult medicine more comfortable for patients and their families.

The Transition team at Martha Eliot provides a medical home for young adults with chronic disease as well as their families. We provide a full range of preventive care through well visits, also urgent care in times of sickness. Our doctors are staff physicians at both Boston Children's Hospital and at Brigham and Women's Hospital, so they have access to a full array of specialists.

Eligibility:
UCLA Medicine - Pediatrics Transition Care Program

The Department of Pediatrics
Division of General Pediatrics

UCLA Medicine - Pediatrics Transition Care Program

The UCLA Med-Peds Transition Care Program helps children with chronic conditions make a smooth transition to adult healthcare. Program experts provide consultation for adolescents and young adults (15 to 25 years old) requiring either specialized medical care for complex conditions (for example, transplant, lupus, sickle cell disease) and/or coordination of healthcare and community-based services.

Our services are available in our UCLA hospitals or in our outpatient office in the Peter Morton Building at 230 UCLA Medical Plaza, located on the Westwood campus.

We provide:
- Transition needs assessments and referrals
- Assistance identifying adult health providers (primary care and specialists)
- Assistance securing insurance, if eligible
- Help improving patient self-care skills
- Patient educational and vocational resources

For more information, contact Debra Loftstein, M.D., M.P.H., director of the Med-Peds Transition Care Program, Loftstein@mednet.ucla.edu or call number below.

CONTACT INFORMATION

Telephone number
(310) 312-9957

PHYSICIANS & SPECIALISTS
Transition Medicine

In 2001 there was a joint consensus by the ACP-AIM, AAP and the AAFP that adolescents and young adults with chronic illnesses need appropriate transitioning of their health care from pediatrics to the adult health care system. Many illnesses once considered to be confined to childhood must now be thought of as disease that begins in childhood but continues into adult life. The number of children and adolescent with chronic medical conditions has increased in the last twenty years primarily due to the advancements in medical sciences. It is estimated that approximately 30 percent of adolescents have at least one chronic illness or disability, and one third of these conditions are moderate to severe. Presently 90 percent of all children with disabilities will live beyond 20 years of age.

Each year in the United States nearly half a million children with special health care needs cross the threshold into adulthood. The median age of survival for a child with the diagnosis of cystic fibrosis is 33 years. It is estimated that there is one million adults in the United States with congenital heart disease (420,000 who have moderate to complex disease) and that number continues to increase at a rate of 5 percent per year. One out of every 640 adults between the ages of 20 and 39 has survived childhood cancer. Many of these patients will need to be followed indefinitely by an adult health care provider that not only knows how to take care of the chronic illnesses they have suffered from their cancer treatment, but also understand that many of them are at risk for early cancers of adulthood such as breast cancer in the survivor of childhood sarcomas.

Transition Medicine Clinic

Baylor Clinic

Dr. Cynthia Peacock, Medical Director
Dr. Hilary Suzawa, Assistant Professor

In January 2006, Baylor’s Combined Medicine-Pediatric Program started a Transition Medicine Clinic with the goal of delivering a medical home to this special population of patients and assisting them and their families with the transitioning of services from the pediatric-subspecialist to the adult-subspecialist. Med-Peds physicians are particularly suited for this role as they are trained to take care of children, adolescents and adults with chronic illnesses. With the help of the Azzam Grant, social worker support started in January 2006. Presently the clinic is taking
Planning a HCT Program
Population Model of HCT

- Medical Home & Care Coordination
- Assessment and Coordination
- Information & Referral

Increasing complexity of YSHCN

Pediatric Care System

Adult Care System
Components of a HCT Health System

Transition Preparation:

- Outreach to youth, families and stakeholders
  - Information and referral
- Education and training for primary care and specialty care pediatric providers
- Integration of HCT assessment, planning and education into primary and specialty care
- Care coordination across transition process
  - Across pediatric and adult health care systems
  - Ages 14 to ? (21, 26, 29…)
- Organized Hand off to adult providers
Components of a HCT Health System

Transition Completion

- Recruitment and training of adult primary care and specialty providers
- Structured connections between pediatric and adult care
  - Disease specific structures
- Ongoing education and coordination for young adults and families
Steps You Can Take to Develop a HCT Program

- Form taskforce with Children’s Hospital Leadership
  - Nursing, SW, PCP, Specialty MDs, Admin
  - Adult system representatives
- Agree on HCT policies and processes for pediatric care
  - Primary care
  - Specialty Care
  - Inpatient Care
  - Nursing and Allied Health
- Implement Pediatric transition education
- Implement care coordination
  - Partner with CMS
- Consider Medical Home Model for the most complex youth and young adults
- Reach out to adult provider
  - Within health care systems
  - By specialty area
Support for HCT Transition

Florida
National
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.
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

Submit
### Your Transition Toolkit

**Change your answers**

<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>
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<td>4</td>
<td>Do you currently use a Transition Readiness Assessment Tool?</td>
<td>No</td>
<td>Transition Readiness Assessment Tool 📂</td>
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<tr>
<td>5</td>
<td>Age range of patients?</td>
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<tr>
<td></td>
<td>12-14</td>
<td></td>
<td>Health and Transition Checklist for Ages 12-14 📂</td>
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<td></td>
<td>15-17</td>
<td></td>
<td>Health and Transition Checklist for Ages 15-17 📂</td>
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<td></td>
<td>18 and older</td>
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<td>10 Steps to Successful Transition 📂</td>
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<td></td>
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<td>When You're 18:</td>
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<td>English 📂</td>
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<td>Envisioning My Future:</td>
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<td></td>
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<td>English 📂</td>
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<td></td>
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<td></td>
<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></td>
<td>Medicaid Info and Insurance Guide 📂</td>
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<td>Information on Guardianship Options 📂</td>
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**For additional resources, visit** [www.floridahats.org](http://www.floridahats.org)
### Transition Readiness Assessment Questionnaire 5.0

**Directions:** Please check the box that best describes your ability level in each of the following skill areas related to your health and health care. There are no right or wrong answers.

<table>
<thead>
<tr>
<th></th>
<th>No, I do not know how</th>
<th>No, but I want to learn</th>
<th>No, but I am learning to do this</th>
<th>Yes, I have started doing this</th>
<th>Yes, I always do this when I need to</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Do you fill a prescription if you need to?</td>
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<tr>
<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>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 your ride 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 fill out the medical history form, including a list of your allergies?</td>
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<tr>
<td>10. Do you keep a calendar or list of medical and other appointments?</td>
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<tr>
<td>11. Do you tell the doctor or nurse what you are feeling?</td>
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<tr>
<td>12. Do you answer questions that are asked by the doctor, nurse or clinic staff?</td>
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<tr>
<td>13. Do you make a list of questions before the doctor’s visit?</td>
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<tr>
<td>14. Do you apply for health insurance if you lose your current coverage?</td>
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<tr>
<td>15. Do you know what your health insurance covers?</td>
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<tr>
<td>16. Do you get financial help with school or work</td>
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<tr>
<td>17. Do you manage your money &amp; budget household expenses (For example: Use checking/debit card)?</td>
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<tr>
<td>18. Do you help plan or prepare meals/food?</td>
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<tr>
<td>19. Do you keep home/room clean or clean-up after meals?</td>
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<tr>
<td>20. Do you use neighborhood stores and services (For example: Grocery stores and pharmacy stores)?</td>
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</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.
    - eHealthInsurance
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.

- **Guardian 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
Florida’s clearinghouse for health care transition information at [www.FloridaHATS.org](http://www.FloridaHATS.org)
For Health Care Providers

If you provide health-related services to young adults with chronic health conditions or disabilities, please be sure you are listed in our Health Services Directory for Young Adults. Visit Submission Instructions to add or update your program information.

Training for Professionals

FREE CME/CEU Credits!

A new training program is now available for free CME/CEU credits through Florida Gulfcoast AHEC. See our brochure on the Health Care Transition Training Program developed by the Institute on Child Health Policy at the University of Florida, and get started today by visiting www.aheceducation.com.

Transition Assessment

- TRAQ 4.1 (JaxHATS transition readiness tool)

Medical Summary Forms

- Health Care Transition Summary (2 page summary to carry at all times)
- Electronic Care Plan (University of Wisconsin)
- Electronic Transition Information Form (HealthyTransitionsNY)
- My Health Passport (Sickkids Good 2 Go Transition Program)

General Checklists & Care Plans

- Transition Timeline (from Shriner’s Hospitals and University of Washington)

Workbooks from the Institute of Child Health Policy at University of Florida and CMS:

- Workbook for Ages 12-14 (English)
- Workbook for Ages 12-14 (Spanish)
- Workbook for Ages 15-17 (English)
- Workbook Ages 15-17 (Spanish)
- Workbook for Ages 18+ (English)
- Workbook for Ages 18+ (Spanish)
Resources

Insurance

Guardianship Issues

Reaching the Age of 18 — Opportunities and Challenges for Young Adults with Disabilities

By the age of majority (18 years), individuals and jurisdictions familiar with the needs and potential of individuals with disabilities are keenly aware of the special challenges that face young adults with disabilities as they transition into adulthood. The guardianship issue is one of the most important decisions that must be made concerning the care and health of adults who continue to need assistance. Guardianship is a legal arrangement where one person (the guardian) is granted the authority by a court to make decisions for another person (the ward) who is unable to make those decisions. Guardianship is a serious responsibility, and it requires commitment, time, and effort. It is important to carefully consider whether guardianship is necessary and, if so, who would be the best person to serve as the guardian.

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

Decision-making is a learned skill. Children and youth who have support and opportunities to practice decision-making skills are more likely to be successful as adults. Children and youth with disabilities may need more help with decision-making than their peers without disabilities. However, with appropriate support and guidance, children and youth with disabilities can learn to make decisions.

Guardianship and Alternatives for Decision-Making Support

Written by Got Transition Staff with support from TIPS Community: DeKalb Trust for Independent Living with Disabilities

Adapted Bright Futures Patient Handout

Links:

- www.FloridaHATS.org
- www.Project10.org
- www.GotTransition.org
- www.RehabWorks.org
- www.211AtYourFingertips.org

Health and Safe Habits:
- Get enough sleep — teens need between 8-10 hours of sleep each night.
- Physical activity — at least 30 minutes/day (walking or playing a sport).
- Limit TV and computer time — no more than 2 hours a day.

Injury and Violence Prevention:
- Always wear a seat belt — it can save your life and the lives of others.
- Pay attention to speed limits.
- Never drink and drive or ride in a car with someone who has been drinking. Designate a driver who does not drink or call someone for a ride if you feel unsafe.
- Use helmets while riding your bike or playing a contact sport.
- Guns are for play and should not be handled for any reason.

Nutrition:
- Eat a balanced diet. Breakfast is important and healthy snacks can prevent being overweight.
- Eat meals as a family — to catch up on the day and keep your family talking.
- Limit sugary foods (such as French fries and chips) and high sugar drinks (soda and sparkling water) to improve your energy and keep your weight under control.

Dental Health:
- Brush your teeth twice a day and floss once a day.
- See your dentist at least once a year.
- Smoking and drinking alcohol can cause stains, tooth decay and mouth cancer.

Sexuality:
- Saying NO to sex is the only way to prevent sexually transmitted infections like gonorrhea, chlamydia, herpes and HIV.
- If you do have sex, use a condom and other effective birth control to prevent pregnancy and some of the STIs.
- Sexual violence is common — communicate clearly with your partner.

Prevention of Substance Use/Abuse:
- Smoking is dangerous to your health — it causes cancer, heart disease and stroke and can be addictive.
- Physical activity — at least 30 minutes/day (walking or playing a sport).
- If you smoke, drink or use illegal drugs talk to your parents or doctor about ways to get help. You can ask to talk to your doctor alone.

School Achievement:
- High school can be demanding and frustrating. Graduating high school is the only guarantee to higher wages and a chance at college.
- Find your own interests and talents and pursue them.
- Getting involved in school activities can make school more fun and enjoyable.

Transition to Adulthood:
- Take responsibility for your health care. Become more independent by making decisions, managing your appointments, and communicating with your doctor. Talk to your parents, teachers, and doctors about what you need to be successful in your activities. That's called self-advocacy.
- Know your rights and responsibilities when you turn 18. Including making decisions about your education, insurance, and other legal matters.
- Know how your health insurance and healthcare needs will change in adulthood.
10 Steps to Successful Health Care Transition

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

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

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

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

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

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

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

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

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

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

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

Visit [www.FloridaHATS.org](http://www.FloridaHATS.org) to find resources and services. Become a fan on Facebook and share your health care transition experiences!
Transition 2 Go

Health Insurance

This is the first in a series of informational briefs called Transition 2 Go. The series will include tips and resources about highlighted health care transition issues that you can take with you and share, wherever you are.

The first issue of Transition 2 Go focuses on health care coverage for transitioning adolescents and young adults. It’s a timely topic given the Supreme Court’s recent decision to uphold major portions of the Affordable Care Act (ACA).

One of the biggest barriers to receiving appropriate health care among young adults is access to adequate health care coverage, especially during early adulthood, the transition period. The U.S. Census Bureau estimates that up to 40% of young adults are uninsured, leaving them without the necessary health care coverage.

To address this issue, the Florida Department of Health’s Division of Vocational Rehabilitation (VR) provides comprehensive, Florida-specific information about insurance options. Visit the VR website at www.myfloridasource.com for more information.

In addition to descriptions of various private and public insurance plans, the guide identifies local state and federal programs for low-income residents, such as those available in Hillsborough, Polk, and Pinellas Counties. The latest issue of the guide also highlights new options currently available.

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 find a job after leaving school.

Any student with a disability may be eligible for VR services starting at age 16. For students who receive special education services, schools often take the lead in referral to VR as part of the student’s 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 of 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, for example, apply at age 16 if leaving high school at age 18. VR can also assist students with community work experience while they are still in high school. Applications can be downloaded at http://www.rehabworks.org/docs/VRApplication.pdf.

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

For more information about this topic, contact Janet Hess at jhess@health.state.fl.us or (813) 259-6604.
Training for Health Care Professionals

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

Health Care Transition Training Program

Training Program Overview

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

Contents of Module 1:
- Introduction to Supportive Caregivers
- Understanding Successful Transitions from Pediatrics to Adult Health Care
- What Is Health Care Transition?
- VHC: an Emerging Issue
- Transition Stages and Issues
- "Bridging"
- Policies and Practices of Health Care Providers and Facilities
- Pediatric and Adult Care: Two Different Cultures
- Transition and Health Insurance
- Transition in Education
- Transition in Vocational Rehabilitation
- Long-Range Needs of Individuals

Contents of Module 2:
- "College and Beyond"
- Developmental Model of Health Care and Child-Care Provider Relationships
- Promoting Transition of Care Relationships
- Health Care Transition Planning Guide
- Transition Resources
- Perspectives From Youth and Young Adults for Doctors and Healthcare Providers
- Transition Resources for the Florida Institute for Child Health Policy, University of Florida

Accreditation

The four-hour-long Health Care Transition Training Program is broken down into two separate modules. The accreditation statements below apply to each module for a total of four 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 and Florida AHEC Network. The University of Florida, University of South Florida, the Florida Department of Health, Florida AHEC, the Florida Medical Association, and the Florida Medical Association Education Foundation, Inc. The Florida AHEC Network is accredited by the Florida Medical Association to provide continuing medical education for physicians. The Florida AHEC Network designates this educational activity for a maximum of 2.0 AMA PRA Category 1 Credit.

www.aheceducation.com
12-14 year old prompts

Patient can name his/her chronic conditions, if any (yes/needs help/no)
Patient can name his/her allergies, if any (yes/needs help/no)
Patient can name his/her medications, if any (yes/needs help/no)
Patient answers questions asked by provider (yes/needs help/no)
Patient asks questions of provider (yes/needs help/no)
Discussed importance of keeping a personal health care record (yes/no)

For YSHCN:
Family is working with patient to help them be independent (yes/no/NA)
Patient has attended an IEP meeting (yes/no/NA)
IEP includes health care transition goals/activities, such as health care self-management (yes/no/NA)
Patient has applied for APD/ Medicaid Home and Community-Based Waiver (yes/no/NA)
Subspecialty Provider Contacts:

15-17 year old prompts

Patient can describe how his/her chronic conditions (if any) impact their health (yes/needs help/no)
Patient can describe how his/her medications (if any) impact their health (yes/needs help/no)
Patient can take his/her medications (if any) without supervision (yes/needs help/no)
Patient has tried to refill a medication (yes/needs help/no)
Patient has scheduled a doctor’s appointment on his/her own (yes/needs help/no)
Patient meets with provider without parents/caregivers present (for part of visit) (yes/no)
Patient is keeping his/her own health care summary (yes/needs help/no)
Patient knows source of own medical insurance (yes/needs help/no)
Patient family are investigating adult doctors for both primary and specialty care (yes/needs help/no)
Patient family are investigating secondary education or vocational opportunities (yes/no)
Patient has received “10 Steps to Successful Health Care Transition” handout (yes/no)

For YSHCN:
Family has begun Voc Rehab application (yes/no/NA)
Family has begun guardianship applications (by age 17) (yes/no/NA)
Subspecialty Provider Contacts:

18-21 year old prompts

Patient has selected a adult doctors for primary and specialty care (yes/no)
* Include name/address for Transfer Summary
Patient can refill own medication (yes/needs help/no)
Patient has insurance/SSI benefits (yes/no)
Patient has received “Just the Facts” insurance guide (yes/no)
Transfer Summary has been/will be forwarded to new providers (yes/no)

For YSHCN:
There is a formal plan in place for post-secondary education/adult living/vocation (yes/no/NA)
Have/Will verbally communicate with new provider(s) (yes/no/NA)
Subspecialty Provider Contacts:
Strategic Planning Guide for Regional Coalitions

January 2010
AAP/ACP/AAFP Transitions Clinical Report

- Published in Pediatrics, July 2011

- Provides framework for developmentally appropriate transition services:
  - For all youth
  - Enhanced planning activities for YSHCN
  - Move from pediatric to adult model of care at age 18-21, even if there is no transfer (e.g., Med Peds, Family Medicine)
  - Within context of a medical home
## Six Core Elements of Health Care Transition (HCT)

<table>
<thead>
<tr>
<th>Pediatric Health Care Setting</th>
<th>Adult Health Care Setting</th>
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<tbody>
<tr>
<td><strong>1. Transition Policy</strong></td>
<td><strong>1. Young Adult Privacy and Consent Policy</strong></td>
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<tr>
<td>• Develop a pediatric health transition policy and share with providers, staff, youth, and families</td>
<td>• Develop a practice young adult privacy and consent policy; share with providers, staff, patients, families</td>
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<tr>
<td>• Educate all staff about HCT best practices</td>
<td>• Educate all staff about privacy and consent practices</td>
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<tr>
<td><strong>2. Transitioning Youth Registry</strong></td>
<td><strong>2. Young Adult Patient Registry</strong></td>
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<tr>
<td>• Identify transitioning youth (current/future) and enroll in a transition registry; monitor all preparation, planning and outcomes (e.g., coordination of care)</td>
<td>• Identify enroll young adults in a practice registry; indicate levels of complexity; monitor adaptation to young adult model of care; note health/wellness status</td>
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<tr>
<td><strong>3. Transition Preparation</strong></td>
<td><strong>3. Transition Preparation</strong></td>
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<tr>
<td>• Assess and track all readiness for adult health care activities with youth and families</td>
<td>• Discuss young adult model of health care (see definition); explain how to use the primary care practice including all access options</td>
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<tr>
<td>• Use the Transition Readiness Assessment (youth/family) to address gaps in preparation, knowledge, and skills</td>
<td>• Use/continue to use the Transition Readiness Assessment (youth/family) to address gaps in knowledge/skills</td>
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<tr>
<td><strong>4. Transition Planning</strong></td>
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<tr>
<td>• Address all health care transition needs/gaps setting goals together with youth and family</td>
<td>• Offer transitioning youth pre-transfer “get acquainted” materials and/or encounter(s) up to a year before transfer prior to their 1st visit, request their:</td>
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<tr>
<td>• Name and notify adult primary care practice of youth’s pending transfer of care (one year out) and arrange for individualized introduction</td>
<td>• for all youth and young adult patients develop, use and update the HCT Action Plan, Portable Medical Summary, and Emergency Care Plan</td>
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<tr>
<td><strong>5. Transition and Transfer of Care</strong></td>
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<tr>
<td>Transfer from pediatric to new adult care location:</td>
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<tr>
<td>• Ensure direct communication with adult PCP and team (email, phone, in person “handshake”)</td>
<td>• Review Transfer of Care Checklist (pediatric/young adult) sent in the “Transition Package” to prepare for initial visit</td>
</tr>
<tr>
<td>• Use the tool: Transfer of Care Checklist (pediatric/young adult)</td>
<td>• Talk with and receive communications from pediatric PCP/team (email, phone, in person “handshake”)</td>
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<tr>
<td>• Send a “Transition Package” containing a transfer letter and items named above and in the Transfer of Care Checklist</td>
<td>• Provide office visit/encounters for transitioning young adults and continue with transition preparation and planning as needed</td>
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<tr>
<td>• Initiate or coordinate specialty transitions as appropriate</td>
<td>• Transition to young adult model of care in same location:</td>
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<tr>
<td>• Transition to young adult model of care in same location: See Core Elements 3, 4, and 5 in the right-hand column</td>
<td>• Clarify PCP and coordinator of care contacts for young adult patient; implement Core Elements 3 and 4 as indicated; assist ongoing specialty care transfers</td>
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<tr>
<td><strong>6. Transition Completion</strong></td>
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<tr>
<td>• Pediatric PCP/team are a resource for each transferred patient and their adult PCP/team following care transfer. Pediatric PCP/team makes contact with adult PCP/team ~3 months post transfer to ensure success and continuity of care</td>
<td>• Consult with pediatric PCP/team as needed; each young adult is integrated using a young adult model of care; the adult practice declares successful and complete HCT</td>
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<tr>
<td>• Transition/transfer is declared complete</td>
<td>• Continue forward with a young adult model of care and appropriate care planning for all patients</td>
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