Systems of Care for Children and Adolescents with Developmental Disabilities

March 29, 2018
Transition to Adult Care
Disability Criteria in Adulthood

• The inability to engage in any substantial gainful activity (SGA) by reason of any medically determinable physical or mental impairment(s) which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months.

Source: Social Security Administration web site: www.ssa.gov/disability/professionals/bluebook/general-info.htm
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 ongoing patient-centered adult care.
What Can Happen?

• Without adequate support in moving from pediatric to adult care, youth may:
  
  o Loss/gaps in insurance
  o Have poor connections to the adult health care system
  o Have decreased adherence with medicine, self-care
  o Increased ER visits, hospitalizations
  o 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.
Why Do Adolescents Need a Structured Health Care Transition Process?

- **Evidence of need for transition services**
  - Nationally, only 16.5% of youth with special health care needs, and 14.2% without special health care needs, received the services necessary to make transitions to adult care
  - Florida is below national average: 7.5% of youth with special health care needs, and 7.0% without special health care needs, received the necessary services

- **Evidence of improved outcomes with a structured approach**
  - Evaluation studies indicate improvement in population health (adherence to care, perceived health and quality of life, self-care); increased patient and family satisfaction; decreased barriers to care; improved utilization of ambulatory care in adult settings; reduced hospitalizations

*2016 National Survey of Children's Health, [http://childhealthdata.org](http://childhealthdata.org)
Gabriel et al. *J Pediatr* 2017Sep;188:263-269
“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.”
### AAP/AAFP/ACP Clinical Report on Health Care Transition*

- In 2011, Clinical Report on Transition published as joint policy by AAP/AAFP/ACP
- Targets all youth, beginning at age 12
- Algorithmic structure with:
  - Branching for youth with special health care needs
  - Application to primary and specialty practices
- Extends through transfer of care to adult medical home and adult specialists
- CR reaffirmed by AAP in 2016; updated CR currently in approval process in AAP, AAFP, ACP

<table>
<thead>
<tr>
<th>Age</th>
<th>Activity</th>
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</thead>
<tbody>
<tr>
<td>12</td>
<td>Youth and family aware of transition policy</td>
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<tr>
<td>14</td>
<td>Health care transition planning initiated</td>
</tr>
<tr>
<td>16</td>
<td>Preparation of youth/parents for adult approach to care; discussion of preferences and timing for transfer to adult health care</td>
</tr>
<tr>
<td>18</td>
<td>Transition to adult approach to care</td>
</tr>
<tr>
<td>18-22</td>
<td>Transfer of care to adult medical home and specialists with transfer package</td>
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</table>

*Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home (Pediatrics, July 2011)
Six Core Elements Approach to Health Care Transition

1. **Transition Policy**
   - Discuss Transition Policy
   - Ages 12-14

2. **Transition Tracking and Monitoring**
   - Track progress
   - Ages 14-18

3. **Transition Readiness**
   - Assess skills annually
   - Ages 14-18

4. **Transition Planning**
   - Develop transition plan, including medical summary
   - Ages 14-18

5. **Transfer/Integration into Adult-Centered Care**
   - • Transfer to adult-centered care
     • Integration into adult practice
   - Ages 18-21

6. **Transition Completion and Ongoing Care**
   - • Confirm transfer completion
     • Elicit consumer feedback
   - Ages 18-26
Six Core Elements Process
Approach and Tools

- Based on the 2011 AAP/AAFP/ACP Clinical Report
  - QI learning collaboratives in DC*, MA, NH, WI, MN, CO using IHI breakthrough approach
- Six Core Elements in three packages with sample tools for each core element
  - Includes measurement options
  - Can be used by all members of the health care team
- 7th grade reading level, Spanish translation available
- FREE (download from www.gottransition.org)
- CUSTOMIZABLE tools and process
  - Use what works for your clinical setting
  - Use your own logos on the tools
- Many models (clinics, programs, consultative services) have incorporated the 6 Core Element Process

Six Core Elements Packages
See www.gottransition.org

Transitioning Youth to Adult Health Care Providers
(Pediatric, Family Medicine, and Med-Peds Providers)

Transitioning to an Adult Approach to Health Care Without Changing Providers
(Family Medicine and Med-Peds Providers)

Integrating Young Adults into Adult Health Care
(Internal Medicine, Family Medicine, and Med-Peds Providers)
Pediatric Core Element #1: POLICY

- **Purpose**
  - Formalize practice’s approach, reduce clinician variability, offer a transparent explicit approach to youth/young adults and families
  - Voted most important element by youth and families

- **Content**
  - Define practice approach and recommended ages for transition preparation for adult-focused care, transfer, and integration into adult care
  - *Key point:* Clarify and practice an adult approach to care at age 18 (including legal changes)
  - Include youth/young adult and family input
  - Reading level should be appropriate

- **Post**
  - Communicate it to all involved early in the process
Many validated tools are available, such as Got Transition and the TRAQ
Tools Adapted for Patients with IDD

There are also readiness tools for youth with ID/DD and their families at www.gottransition.org/resources/index.cfm#developmentaldisabilitiesandtransition
# Transition Planning Activities

## Planning tasks

<table>
<thead>
<tr>
<th>Activity</th>
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<tbody>
<tr>
<td>Develop and regularly update the plan of care, including readiness assessment findings, goals and prioritized actions, medical summary and emergency care plan, and, if needed, a condition fact sheet and legal documents. Documents could also be utilized by client/caregiver to create their own medical binder.</td>
</tr>
<tr>
<td>Prepare youth and parent/caregiver for adult approach to care at age 18, including changes in decision-making and privacy and consent, self-advocacy, and access to information.</td>
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<tr>
<td>Determine level of need for decision-making supports for youth with intellectual challenges; make referrals to legal resources.</td>
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<tr>
<td>Plan with youth/guardian for optimal timing of transfer.</td>
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<tr>
<td>Obtain consent from youth/guardian for release of medical information.</td>
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<tr>
<td>Assist youth in identifying an adult provider and communicate with selected provider about pending transfer of care.</td>
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<tr>
<td>Provide linkages to insurance resources, self-care management information, and culturally appropriate community supports.</td>
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Sample Transfer of Care Checklist
Six Core Elements of Health Care Transition 2.0

Patient Name: __________________ Date of Birth: ____________

Primary Diagnosis: ______________ Transition Complexity: ____________  
Low, moderate, or high

-Prepared transfer package including:
  - Transfer letter, including effective of date of transfer of care to adult provider
  - Final transition readiness assessment
  - Plan of care, including transition goals and pending actions
  - Updated medical summary and emergency care plan
  - Guardianship or health proxy documents, if needed
  - Condition fact sheet, if needed
  - Additional provider records, if needed

-Sent transfer package __________ Date

-Communicated with adult provider about transfer __________ Date
One of the most effective transition tools is physician-to-physician communication.

Sample Transfer Letter
Six Core Elements of Health Care Transition 2.0

Dear Adult Provider,

*Name* is an *age*-year-old patient of our pediatric practice who will be transferring to your care on *date of this year*. *His or her* primary chronic condition is *condition*, and *his or her* secondary conditions are *conditions*. *Name’s* related medications and specialists are outlined in the enclosed transfer package that includes *his or her* medical summary and emergency care plan, plan of care, and transition readiness assessment. *Name* acts as *his or her* own guardian, and is insured under *insurance plan* until age *age*.

I have had *name* as a patient since *age* and am very familiar with *his or her* health condition, medical history, and specialists. I would be happy to provide any consultation assistance to you during the initial phases of *name’s* transition to adult health care. Please do not hesitate to contact me by phone or email if you have further questions.

Thank you very much for your willingness to assume the care of this young *man or woman*.

Sincerely,
Is There a Way to Bill for Transition Services?

- Got Transition and the American Academy of Pediatrics developed a transition payment tip sheet to support the delivery of recommended transition services in pediatric and adult primary and specialty care settings.

- The 2017 tip sheet provides a comprehensive listing of transition-related CPT codes, corresponding Medicare fees and several clinical vignettes.

Population Model of HCT
National Center for Health Care Transition Improvement

http://www.gottransition.org/
### Six Core Elements of Health Care Transition

Listed in the table below are PDFs of the sample tools used in the Six Core Elements of Health Care Transition. Complete packages are available to download and customize for your practice or plan.

<table>
<thead>
<tr>
<th>Transitioning Youth to Adult Health Care Providers (Pediatric, Family Medicine, and Med-Peds Providers)</th>
<th>Transitioning to an Adult Approach to Health Care Without Changing Providers (Family Medicine and Med-Peds Providers)</th>
<th>Integrating Young Adults into Adult Health Care (Internal Medicine, Family Medicine, and Med-Peds Providers)</th>
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</tr>
<tr>
<td>Complete Package</td>
<td>Complete Package</td>
<td>Complete Package</td>
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<tr>
<td>Full Package</td>
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<tr>
<td>En Español</td>
<td>En Español</td>
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<tr>
<td>Editable Version</td>
<td>Editable Version</td>
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### Transitioning Policy

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<th>1) Transition Policy</th>
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<tbody>
<tr>
<td>Transition Policy</td>
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<tr>
<td>En Español</td>
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### Transition Tracking and Monitoring

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<th>2) Transition Tracking and Monitoring</th>
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<tr>
<td>Individual Transition Flow Sheet</td>
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<tr>
<td>En Español</td>
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<tr>
<td>Transition Registry</td>
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<td>En Español</td>
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### Transition Readiness

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<th>3) Transition Readiness</th>
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<tr>
<td>Transition Readiness Assessment for Youth</td>
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<tr>
<td>Trans. Readiness Assessment for Parents/Caregivers</td>
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<td>En Español</td>
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### Transition Planning

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<th>4) Transition Planning</th>
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<tbody>
<tr>
<td>Plan of Care</td>
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<tr>
<td>En Español</td>
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<tr>
<td>Medical Summary and Emergency Care Plan</td>
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<td>En Español</td>
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### Transfer of Care

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<th>5) Transfer of Care</th>
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<tr>
<td>Transfer of Care Checklist</td>
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<tr>
<td>En Español</td>
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<tr>
<td>Transfer Letter</td>
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### Transfer Completion

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<th>6) Transfer Completion</th>
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<tr>
<td>Health Care Transition Feedback Survey for Youth</td>
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<tr>
<td>En Español</td>
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<td>Health Care Transition Feedback Survey for Parents/Caregivers</td>
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### Measurement

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<tr>
<td>Measurement</td>
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Florida’s clearinghouse for HCT information

www.FloridaHATS.org
Florida Health and Transition Services

Welcome to the FloridaHATS Web site! FloridaHATS is a program of Florida Department of Health, Children’s Medical Services Managed Care Plan (CMS Plan). Our mission is to ensure successful transition from pediatric to adult health care for all youth and young adults in Florida, including those with disabilities, chronic health conditions or other special health care needs. To learn more about our program, visit About Us.

Tool Box

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

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

Regional Coalitions
- HillsboroughHATS
- Northeast FloridaHATS
- PanhandleHATS
- South FloridaHATS

Some Resources

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

Some Materials for Youth and Families

- Just the Facts: The 411 on Health Insurance for Young Adults 19-30 in Florida (2018)
- Transition 2 Go Informational Briefs on Guardianship, Employment, Social Security, and

Some Tools for Providers

- Condition-Specific Tools for Subspecialists from the American College of Physicians; tools are now available for the following subspecialties: general internal medicine, intellectual/developmental disabilities and physical disabilities
- Illinois Transition Care Project Offers

Need Training?

- Health Care Transition Training for Health Care Professionals. This course is appropriate for all practitioners and support staff involved in the care of adolescents and young adults.
Health Care Transition Preparation for Youth and Young Adults with Special Health Care Needs in Florida

**Incorporate transition planning in chronic care management. Coordinate with CMS Nurse if patient is enrolled in CMS.**

**Step 1:**
- Provide age-appropriate counseling and transition materials to youth and family.
- Identify AID eligibility and education needs.
- See local 2-1-1 Helpline for other social services.
- Is patient 12-14 years? 
  - Yes: See action steps for specific age ranges.
  - No: Is patient 15-17 years?
    - Yes: Ensure Step 1.
    - No: Is patient 18-21 years?
      - Yes: Determine services needed.
      - No: Action coordinates support.

**Step 2:**
- Ensure Step 1. Assess transition readiness (TRAC or other tool).
- Explore post-high school options; identify decision-making needs.
- Establish timeline for transfer to adult primary and subspecialty care.
- Does patient have ID? 
  - Yes: Provide 411 Insurance Guide (handout) and local contact information.
  - No: Initiate follow-up interaction.

**Step 3:**
- Ensure Steps 1 and 2.
- Identify insurance coverage, adult service and employment needs.
- Transfer to adult primary and subspecialty care.
- Is patient eligible for Medicaid Waiver program? 
  - Yes: See handout on Medicaid Waiver programs. For patients with ID/DD, APD does intake; send all patient documents to APD.
  - No: See handout on Medicaid Waiver programs for patients with ID/DD.
- Is patient eligible to apply? 
  - Yes: See handout on Medicaid Waiver programs.
  - No: Is patient enrolled in APD?
    - Yes: See handout on Medicaid Waiver programs.
    - No: See handout on Medicaid Waiver programs for patients with ID/DD.

**Determination of Services Needed:**
- Insurance patient will have as adult? 
  - Yes: Discharge SSI/private and public insurance options with youth/family.
  - No: Abbreviation of major issues before patient’s 18th birthday. (18th birthday. (Advance directive, medical services, education, insurance, and other legal needs). Refer youth/family to Florida Local Services for legal aid; refer patient to local Center for Independent Living for additional guidance. (Handout)

**Action Steps for Specific Age Ranges:**
- Age Ranges
  - Step 1: Provide age-appropriate counseling and transition materials to youth and family.
  - Step 2: Assess transition readiness (TRAC or other tool).
  - Step 3: Transfer to adult primary and subspecialty care.

**Care Coordination Support:**
- Have age-appropriate transition issues been addressed?
  - Yes: Transition component interaction complete.
  - No: Initiate follow-up interaction.

**Glossary:**
- APD: Agency for Persons with Disabilities
- CMS: Children’s Medical Services, Department of Health
- ID/DD: Individuals with intellectual or developmental disabilities
- APD: Agency for Persons with Disabilities
- TRAC: Transition Readiness Assessment Questionnaire 5.0 (or use other checklist)
- VR: Vocational Rehabilitation Program

*Handouts are available in English, Spanish, and Haitian Creole at www.FloridaHATS.org
Plan of Care

Sample Plan of Care
Six Core Elements of Health Care Transition 2.0

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

Name: ___________________________  Date of Birth: ___________________________
Primary Diagnosis: ___________________________  Secondary Diagnosis: ___________________________

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

<table>
<thead>
<tr>
<th>Prioritized Goals</th>
<th>Issues or Concerns</th>
<th>Actions</th>
<th>Person Responsible</th>
<th>Target Date</th>
<th>Code Complete</th>
</tr>
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Initial Date of Plan: ________________  Last Updated: ________________  Parent/Caregiver Signature: ___________________________

Clinician Signature: ___________________________  Care Staff Contact: ___________________________  Care Staff Phone: ___________________________

© Get Transition™ Center for Health Care Transition Improvement, 01-2014. Get Transition™ is a program of The National Alliance to Advance Adolescent Health supported by U301MC76729 HRSA/NIH/AAH. www.GetTransition.org
Self-Advocacy Guides

www.floridahats.org/?page_id=616
Self-Management Videos

Short Videos
with step-by-step instructions
School

- Incorporate self-advocacy and self-management skills in school IEP
- Transition IEPs, which are introduced at age 14 in Florida, should outline a pathway to post-secondary independent living
- Project 10 ([www.project 10.info](http://www.project 10.info)) is Florida Department of Education’s statewide transition initiative
  
  ○ Includes employment training, post-secondary education and independent living resources
Classroom Curriculum

Parent/Student Handouts

Lesson Plans
Health Insurance

- Plan for change in insurance coverage
  - Medicaid
  - Parents’ plan
  - Employer-based
  - Marketplace plans
  - Plan for change in insurance coverage
Sexual Health

• High incidence of sexual abuse among persons with intellectual and developmental disabilities
  ○ Most abusers are service providers

• Lack of education about how to properly act on urges can cause major issues
  ○ Unacceptable public displays
  ○ Unwarranted sexual harassment

• Sexuality & Developmental Disabilities Across the Lifespan
  ○ Helps educators and family members assist with exploration of self and sexuality
• Individuals with a developmental disability should apply to APD as early as age 3

• Don’t wait to get on the Home and Community – Based Waiver Waiting List (called iBudget)
Age of Majority

• Legal responsibilities
  ○ Financial
  ○ Decision-Making
  ○ Florida Bar’s #JustAdulting Legal Survival Guide for new adults
    www.justadulting.com/

• Disability benefits determined by ability to work
Decision-Making

- Consider decision making options, such as guardian advocacy
- Explore long-term financial planning options, such as a special needs trust
Decision-Making

See Nemours video at https://youtu.be/CpvIyfiRjRM
Supplemental Security Income

- Redetermination at age 18
- Stricter eligibility requirements
Employment

• Apply to Division of Vocational Rehabilitation 2 years before leaving high school

• Can help pay for post-secondary education and job training programs

• Assists in job placement

Transition 2 Go
in Florida

School to Work Transition
Vocational Training

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 16. For students who receive special education services, schools often take the lead in referral to VR as part of the student’s transition Individualized Education Plan (IEP). However, having an IEP is not a VR eligibility requirement. 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 can also assist students with community work experience while they are still in high school. Applications can be downloaded at http://rehabworks.org/docs/VRappication.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/SchooltoWork.pdf.

In addition to VR, CareerSource Florida offers job training for income eligible clients, including youth ages 14-21. Visit www.careersourceflorida.com for more information.
College Resources for Students with Disabilities

- Scholarships and Financial Aid for Students with Disabilities, from accreditedschoolsonline.org
- Study Tips for College Students with Dyslexia and Dysgraphia
- Studying with ADHD
- Going to College with ASD
- Thriving in Trade School with a Disability
- Headed for College with Special Health Care Needs (YouTube video)
  Dr. Kitty O’Hare of Boston Children’s Hospital, provides practical considerations for a student’s health care transition, in preparation for a successful adjustment to college life, prepared by Got Transition.
- Radio Episodes from Got Transition
  - Radio Episode 2
    Healthcare Transition & College- It Doesn’t Have to be Learned the Hard Way!
  - Radio Episode 3
    Healthcare Transition & College- It Doesn’t Have to be Learned the Hard Way! Part 2
- Transitioning from High School to Post-Secondary Education, article by Dr. Marilyn Bartlet, Texas A&M
- Resources for College Students from BestColleges.com, including information on disability, mental health, academics and college life

Transfer of Care

- Transfer of care
  - Primary Care
  - Specialty Care

www.floridahats.org/service-directory/search-service-directory
Web-Based Training for Professionals

• Cross-disciplinary training for practitioners in the clinical setting
  o 10 modules, 15-20 minutes each
  o Free CME/CE for physicians, physician assistants, LPNs, RNs, and other allied health professionals, through Florida AHEC Network at www.aheceducation.com
  o Modules also posted on www.FloridaHATS.org

• Training for teachers, school nurses and other professionals in the school setting
  o Available at www.FloridaHATS.org
Other Transition Resources

- **Assistive Technology and Equipment**: FAAST
- **Independent Living**: Centers for Independent Living
- **Housing**: Housing in Florida: A Resource Guide for Individuals with Developmental Disabilities
- **Transportation**: Access to Florida’s Transportation Disadvantaged Program for Individuals with Disabilities