Youth with Special Health Care Needs: Transition from Pediatric to Adult Health Care

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Department of Pediatrics, Adolescent Medicine

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Agenda

- Background
- How Are We Doing?
- Current Policy
- Tools and Resources
- How Can You Help?
Background
Developmental Disability

- A severe, chronic disability of an individual that is attributable to a mental or physical impairment or combination of mental and physical impairments
  - Is manifested before the individual attains age 22;
  - Likely to continue indefinitely;
  - Results in substantial functional limitations in 3 or more of the following areas of major life activity: self-care; receptive and expressive language; learning; mobility; self-direction; capacity for independent living; economic self-sufficiency;
  - Reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.

• Children and youth with special health care needs (CYSHCN) are those who “have or are at increased risk for a chronic physical, developmental, behavioral or emotional condition who also require health and related services of a type or amount beyond that required by children generally.”

Source: Pediatrics; Volume 102, Nov/July 1998
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 on-going patient-centered adult care.
Changing Epidemiology of Childhood Conditions

**Congenital Heart Disease**
- ~1,000,000 adults in the U.S. have CHD
- Slightly more adults than children

**Cerebral Palsy**
- Up to ~1,000,000 people in U.S. have CP
- Lifespan approaching that of general population

Sources: Centers for Disease Control and Prevention, [www.cdc.gov/ncbddd/heartdefects/data.html](http://www.cdc.gov/ncbddd/heartdefects/data.html) (2016)

Sickle Cell Disease

Prevalence

24.4% of youth aged 12-17 have SHCN

What Can Happen?

- Without adequate support in moving from pediatric to adult care, youth may:
  - Loss/gaps in insurance
  - Have poor connections 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.”
What Are the Issues?
### Cognitive Development: Piaget’s Formal Operational Thought

<table>
<thead>
<tr>
<th></th>
<th>EARLY (11-13)</th>
<th>MIDDLE (14-16)</th>
<th>LATE (17-21)</th>
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<tr>
<td>Concrete thought</td>
<td>No future perspective</td>
<td>Abstraction</td>
<td>Established abstract thought</td>
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<td></td>
<td></td>
<td>Has future perspective; not always used</td>
<td>Future oriented</td>
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The Adolescent Brain

- 10-year NIH MRI study
- 5-20 y.o. participants
- Brain continues to change until mid 20s

## Culture Shock

### Professional culture and traditions

<table>
<thead>
<tr>
<th>Pediatrics</th>
<th>Adult Physicians</th>
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<tr>
<td>o Child-friendly</td>
<td>o Cognitive</td>
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<td>o Family-centered</td>
<td>o Patient-centered</td>
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<tr>
<td>o Interact primarily with parents</td>
<td>o Interact with patient</td>
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<td>o Nurturing</td>
<td>o Empower individual</td>
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<td>o Prescription</td>
<td>o Collaborative</td>
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<td>o Developmental Focus</td>
<td>o Disease Focus</td>
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Communication Gaps

Among providers

Pediatric knowledge of adult system physicians, resources and services

Lack of systematic transfer of records and co-management of care during transition

Between adult provider and youth
Adult System of Care

- Provider capacity and training
- Lack of physicians who are
  - Trained in pediatric onset conditions
  - Willing to take primary responsibility for care
- Service fragmentation
  - Minimal case management in adult practices
  - Lack of linkages to community-based adult services
- Low Medicaid reimbursement rates
Adequate Insurance Coverage

- Aging out of childhood health insurance plans can create gaps/loss in coverage
- Benefits in temporary jobs often limited, unavailable, or have high premiums
- Increased salary may lower/eliminate public benefits
- Limited benefits provided in adult Medicaid package
Discussion

Think about how your personal experience with health insurance as a young adult - or the experience of a young adult whom you know - has been impacted by federal and/or state level policies. Have they been positive or negative experiences?
How Are We Doing?
2016 National Survey of Children’s Health

- Starting in 2016, survey administered annually
- Web-based survey among parents of children aged 0-17
- Includes HCT measures for all youth aged 12-17, with and without SHCN
- Questions about anticipatory guidance from provider:
  - Discussed changing health care needs in adulthood
  - Talked about transitioning to adult care
  - Talked to youth privately
  - Worked with youth to gain self-management skills

Performance

YSHCN

Received services necessary to make transitions to adult health care
Children with special health care needs age 12-17 years

Non-YSHCN

Received services necessary to make transitions to adult health care
Children without special health care needs age 12-17 years

Current Policy
Goals for Transition

• Manage their own health
  o Disease self-management
  o 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

Joint Clinical Report on Transitions

- Published in *Pediatrics*, July 2011
  - Joint report from AAP / AAFP / ACP

- Provides framework for developmentally appropriate transition services:
  - For all youth starting at ages 12-14
  - Enhanced planning activities for YSHCN
  - Move from pediatric to adult model of care at age 18, even if there is no transfer (e.g., Family Medicine, Med Peds practice)
  - Within context of a medical home
National Center for Health Care Transition Improvement

http://www.gottransition.org/
Six Core Elements of HCT
For Primary and Specialty Care

1. Develop Transition Policy
2. Establish Tracking and Monitoring
3. Assess Transition Readiness
4. Transition Planning
5. Transfer of Care
6. Transfer Completion
### 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</th>
<th>Transitioning to an Adult Approach to Health Care Without Changing Providers</th>
<th>Integrating Young Adults into Adult Health Care</th>
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<tr>
<td><strong>Complete Package</strong></td>
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<td>- Full Package</td>
<td>En Español</td>
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<td>Integrating Young Adults into Adult Health Care</td>
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#### 1) Transition Policy

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<tr>
<th>Transition Policy</th>
<th>Transition Policy</th>
<th>Young Adult Transition and Care Policy</th>
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<tr>
<td>Transition Policy</td>
<td>En Español</td>
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#### 2) Transition Tracking and Monitoring

<table>
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<tr>
<th>Individual Transition Flow Sheet</th>
<th>En Español</th>
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<td>Transition Registry</td>
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#### 3) Transition Readiness

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#### 4) Transition Planning

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<tr>
<td>Medical Summary and Emergency Care Plan</td>
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<td>Condition Fact Sheet</td>
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#### 5) Transfer of Care

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<tr>
<th>Transfer of Care Checklist</th>
<th>En Español</th>
<th>Self-Care Assessment for Young Adults</th>
<th>En Español</th>
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<tr>
<td>Transfer Letter</td>
<td>En Español</td>
<td>Health Care Transition Feedback</td>
<td>En Español</td>
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#### 6) Transfer Completion

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<tr>
<th>Health Care Transition Feedback Survey for Young Adults</th>
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</tbody>
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**Measurement**

- Health Care Transition Feedback Survey for Young Adults | En Español
- Health Care Transition Feedback Survey for Parents/Caregivers | En Español
- Health Care Transition Feedback Survey Young Adults | En Español
Resources for Florida Practitioners
Florida’s clearinghouse for HCT information
www.FloridaHATS.org
Florida Health and Transition Services

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

Tool Box

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

For Health Care Practitioners

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

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

Contact
- Archive

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

- Transition 2 Ge International Briefs On Florida Guardianship, Employment, Social Security, and
- Condition-Specific Tools for Subspecialists From the American College of Physicians, tools are now available for the following subspecialty: general internal medicine (intellectual developmental disabilities and physical disabilities)

Need Training?

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

1. **Step 1**
   - Provide age-appropriate counseling and transition materials to youth and family.
   - Identify APD eligibility and education needs.
   - Explore post-high school options, identify decision-making needs.
   - Establish timeline for transfer to adult primary and subspecialty care.

2. **Step 2**
   - Ensure Step 1.
   - Assess transition readiness (TRAG or other tool).
   - Explore post-high school options, identify decision-making needs.
   - Refer patient to local services/programs.

3. **Step 3**
   - Ensure Steps 1 and 2.
   - Identify insurance coverage, adult service and employment needs.
   - Transfer to adult primary and subspecialty care.

**Determination of Services Needed**

- **Insurance patient will have as adult?**
  - Yes
  - No

**Care Coordination Support**

- Have age-appropriate transition issues been addressed?
  - No
  - Yes

**Glossary**

- APD: Agency for Persons with Disabilities
- CMS: Children's Medical Services, Department of Health
- I/DD: Individuals with intellectual or developmental disabilities
- IEP: Individual Educational Plan
- TRAG: Transition Readiness Questionnaire 5.0 (or use other checklist)
- VR: Vocational Rehabilitation Program

*Handouts are available in English, Spanish, and Haitian Creole at [www.FloridaHATS.org](http://www.FloridaHATS.org)*
Readiness Assessment

Sample Transition Readiness Assessment for Youth
Six Core Elements of Health Care Transition 2.0

Please fill out this form to help us see what you already know about your health and how to use health care and the areas that you need to learn more about. If you need help completing this form, please ask your parent/caregiver.

Date:
Name: ___________________________ Date of Birth: __________

Transition Importance and Confidence
On a scale of 0 to 10, please circle the number that best describes how your level of confidence.

How important is it for you to prepare for change to an adult doctor before age 22?

0 (not important) 1 2 3 4 5 6 7 8 9 10 (very important)

How confident do you feel about your ability to prepare for change to an adult doctor?

0 (not confident) 1 2 3 4 5 6 7 8 9 10 (very confident)

Managing Medications
1. Do you fill a prescription if you need to?
2. Do you know what to do if you are having a bad reaction to your medications?
3. Do you take medications correctly and on your own?
4. Do you receive medications before they run out?

Appointment Keeping
5. Do you call the doctor's office to make an appointment?
6. Do you follow up on any referral for tests, check-ups or labs?
7. Do you arrange for your ride to medical appointments?
8. Do you call the doctor about unusual changes in your health? (For example: Allergic reactions?)
9. Do you apply for health insurance if you lose your current coverage?
10. Do you know what your health insurance covers?
11. Do you manage your money and budget household expenses? (For example: use checking/debit card?)

Tracking Health Issues
12. Do you fill out the medical history form, including a list of your allergies?
13. Do you keep a calendar or list of medical and other appointments?
14. Do you make a list of questions before the doctor's visit?
15. Do you get financial help with school or work?

Talking with Providers
16. Do you tell the doctor or nurse what you are feeling?
17. Do you answer questions that are asked by the doctor, nurse, or clinic staff?

Managing Daily Activities
18. Do you help plan or prepare meals?
19. Do you keep home/homework clean or clean-up after meals?
20. Do you use neighborhood stores and services? (For example: Grocery stores and pharmacy stores?)

© Wood, Sawicki, Reiss, Livingood & Kremer, 2014
### 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 transition package along with the latest transition readiness assessment, medical summary and emergency care plan, and, if needed, a condition fact sheet and legal documents.

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

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

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

Initial Date of Plan: __________
Last Updated: __________
Parent/Caregiver Signature: __________
Clinician Signature: __________
Care Staff Contact: __________
Care Staff Phone: __________

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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
Transition for Students with Disabilities
How Parents Can Be Effective Advocates in the IEP Meeting

If you’re a parent of one of the 5 million children with disabilities in the U.S., you’ve probably been to the Individual Educational Plan (IEP) meeting. Under the Individuals with Disabilities Education Act (IDEA), parents of a child who receives special education services must at least once a year with representatives of the local school district to prepare their child’s IEP - a detailed, written description of the child’s educational program.

You don’t need to be a special education expert to be an effective advocate for your child in the IEP process. What you must do is be prepared and plan ahead. Every parent - whether it’s their first or their 10th IEP meeting - will benefit from reviewing these 10 Steps in advance of the meeting.

Step 1: Understand your child’s legal rights to special education.
Your school district is required by IDEA to give you notice of special education services, regulations and policies. Read these carefully. Keep in mind that under the law, parents are equal partners with school representatives in decision-making. You are just as important as everyone else at the IEP meeting.

Step 2: Obtain a copy of your school district’s IEP form.
Becoming familiar with the sections you will be filling out at the IEP meeting, which typically include:
- Program or Class - the appropriate learning environment for your child, such as a regular classroom for all or part of the school day, a special class or a private school
- Goals and Objectives - the general academic, linguistic, social, communication, vocational, cognitive, self-help and other goals you have for your child, such as reading or math skills, healthy peer relationships or independent living skills. Plus, the specific steps your child will have to take to reach these goals.
- Related Services - developmental, corrective and other services necessary to support your child’s placement in a regular class or to allow your child to benefit from special education. Examples include one-to-one aide in the classroom, speech therapy, or transportation to and from school.

When age 14 and older that will help them meet postsecondary setting, employment, and Independent living. Transition services for those for students who are 14 and older, including the child’s educational performance and records.

Getting health insurance
Are you covered? Coverage of Transplants. Insurance Options Before Age 18.

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
Becoming an Adult:
Legal and Financial Planning

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
Transfer of Care

Health Services Directory

The Health Services Directory will help you to search for health care programs and providers in your area that serve young adults, including those with disabilities or chronic health conditions.

- Search the Health Services Directory
- Submit a new entry
- Recommend a program or provider
- Update an existing entry
- Find related service directories in Florida

Please help us keep the directory up-to-date! We encourage both consumers and providers to let us know about resources you think should be included. For instructions on how to add a service, update an existing entry, or recommend a program, please visit our Directory Submission Page.

Disclaimer: A listing in this directory does not imply an endorsement from FloridaHATS, Children’s Medical Services, or Florida Department of Health. 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:

- [FloridaHATS](www.floridahats.org/service-directory/search-service-directory)
College Students with Disabilities

Secondary & Post-Secondary Education

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 Dsygraphia
- Studying with ADHD
- Going to College with ASD
- Thriving in Trade School with a Disability
- Heading 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 Bartlett, Texas A&M
- Resources for College Students from BestColleges.com, including information on disability, mental health, academics and college life

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
How Can You Help?
What You Can Do

- Establish practice policies for transition to adult care: post them in waiting rooms!
- Encourage independence in managing care
  - Fill prescriptions, take medication, schedule appointments
  - Talk directly to YSHCN first, then to caregiver as needed
- Help YSHCN access adult primary and specialty care providers
  - Establish relationships with adult providers
  - Initiate transfer of care and be available for consultation
- Maintain an up-to-date health care summary for YSHCN that is portable and accessible
What You Can Do

➢ Help YSHCN identify and access adult health insurance coverage
➢ Coordinate linkages to community-based adult services
➢ Work with schools to include HCT goals and activities in IEP and 504 Plans
➢ Review legal rights and responsibilities at 18
➢ Discuss guardianship or decision-making options, if needed
Join an HCT Coalition

Regional Coalitions

Background

Four regions – Tampa/Hillsborough County, Panama City/Panhandle area, Jacksonville/Duval County, and South Florida – have used the MAPP community-based planning approach to begin building local systems that support health care transition.

The coalitions were organized with assistance from local MAPP facilitators, and used our Strategic Planning Guide for Health Care Transition Coalitions to help guide them in the process. Here is a presentation that highlights background and history of coalition development. Links to scheduled meetings and meeting minutes for each coalition are listed below.

- HillsboroughHATS
- Northeast FloridaHATS
- PanhandleHATS
- South FloridaHATS
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
Summing It Up
Contact

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