Florida Health and Transition Services
Year 4 Report / FY 2011-2012

June 21, 2012
Agenda

- Welcome
- Background
- Current Activities
- Looking Forward
- Questions
Presenters

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Background

Year 1

- 2008 legislation for statewide Task Force to assess HCT needs and develop plan

- 2009 Report: Ensuring Successful Transition from Pediatric to Adult Health Care
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

2009 Legislative Report
Florida Strategic Plan for Health Care Transition

1. Health Care Benefits: VYAA obtain and maintain adequate, affordable health insurance.
   - Develop a technical assistance guide to help identify insurance options available to VYAA.
   - Implement a Medicaid Buyin option.
2. Service Compensation: Insurers reimburse providers for services needed to effectively care for VYAA.
   - Work with Medicaid programs to implement medical homes for VYAA.
   - Work with Medicaid program and private insurers to develop policies relating to co-management of VYAA.
   - Advocates for insurance premium to reflect the time and resources required for appropriate care of VYAA.
3. Education and Training: Provide basic education and training to VYAA and their families.
   - Expand DMS network coverage for VYAA age 25 or 29.

Vision
What our State will look like
All youth in Florida, including those with disabilities or special health care needs, will successfully transition to adulthood, including adult health care, work, and independence.

Implementation
How we make strategy a habit
The Task Force, CMS, Office of Health Care Transition, FDBDC, and other partners will:
- Communicate the strategic plan to all stakeholders throughout the state.
- Enable stakeholders in the creation of objectives and strategies to support goals.
- Hold parties accountable for achievement of assigned objectives.
- Monitor the plan quarterly.
- Hold registry schedule and data collection calls to report on progress.
- Change the plan if something is not working, take corrective action, or move to build on success.
- Leverage strategies for performance.
- Celebrate when goals are reached.

www.FloridaHATS.org
Background

- **Years 2-3**
  - Established Florida HATS
  - Start up activities
    - Website, [www.FloridaHATS.org](http://www.FloridaHATS.org)
    - Educational materials
    - Provider training
    - Pilot regional coalitions
Year 4 Activities
CMS Partnership with

Florida Association of Community Health Centers (FACHC) and

Federally Qualified Health Centers (FQHCs)
CMS - FACHC/FQHCs

45 FQHC organizations in FL; 300+ sites
  - Accept Medicaid, uninsured patients

MOA to facilitate smooth transition of YSHCN to FQHC adult medical homes
  - When appropriate, CMS Care Coordinators will refer CMS patients to, and communicate with, FQHC providers
  - FACHC will encourage CMS credentialing among FQHC providers
  - GME/provider training at FQHCs about transition
Regional Coalitions: Panhandle HATS
Eligible Clients:
- CMS clients ages 18-21; uninsured and Medicaid enrolled, who consent to be referred to FQHC for their primary care Medical Home

Partners:
- Escambia Community Clinics, Inc. (FQHC)
- Children’s Medical Services (Pensacola)
- Community Health Information Network (CHIN)/NW Florida RHIO
CMS to Escambia Community Clinic (ECC) FQHC Referral Process

Step 1: CMS Transition client counseled on medical home options. Client consents to FQHC referral and signs CHIN consent.

Step 2: Client information entered in CHIN/CareScope by designated CMS staff. Referral information completed in CareScope referral module.

Step 3: CMS assessment/discharge summary is scanned and attached to electronic referral (any specialty clinical notes will also be attached, i.e., neuro, pulmonary, endocrinology).

Step 4: Referral will be received ("picked up") electronically in Carescope/CHIN by designated ECC/FQHC Social Worker (MSW). One contact will be designated for CMS clients.
Step 5: Referred CMS client will be entered into FQHC electronic medical records system and assigned to appropriate PCMH provider support team. Client will be contacted and appointment will be scheduled.

Step 6: Once patient arrives at ECC/FQHC for appointment, client will be greeted by designated social worker and walked through check in process.

Step 7: ECC/FQHC social worker will remain with CMS transition client through visit.

Step 8: All additional referrals and resources will be provided and coordinated through designated social services staff and PCMH provider support team referral specialist.

Step 9: Designated social worker will continue to be the client’s contact, liaison and advocate (FQHC Case Management Model).
Jacksonville HATS
Instructions: Please select one of the following that best describes you. You will then be asked a series of questions. Resources will be provided to you based on your answers.

Ready? Let's get started!

Which of the following best describes you?

Please select one of the following:

<table>
<thead>
<tr>
<th>Type</th>
<th>Availability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical Provider</td>
<td>No Answers Submitted</td>
</tr>
<tr>
<td>Caregiver or Parent</td>
<td>NA</td>
</tr>
<tr>
<td>Patient</td>
<td>NA</td>
</tr>
<tr>
<td>Case Manager</td>
<td>NA</td>
</tr>
<tr>
<td>Teacher</td>
<td>NA</td>
</tr>
</tbody>
</table>
Medical Provider

To get started, click on the questions below. Resources will be provided to you based on your answer.

Your Transition Toolkit

<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
<th>Resources</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Do you have a Transition Policy established in your practice or facility?</td>
<td>No Answer</td>
<td>NA</td>
</tr>
<tr>
<td>2. Do you use a checklist or other method that helps you identify adolescent patients who may need assistance with Transition?</td>
<td>No Answer</td>
<td>NA</td>
</tr>
<tr>
<td>3. Do you currently provide your patients with a portable health summary after each visit?</td>
<td>No Answer</td>
<td>NA</td>
</tr>
<tr>
<td>4. Do you currently use a Transition Readiness (TRAQ 4.1) Assessment Tool?</td>
<td>No Answer</td>
<td>NA</td>
</tr>
<tr>
<td>5. Age range of patients?</td>
<td>No Answer</td>
<td>NA</td>
</tr>
</tbody>
</table>
Do you focus on Health Care Transition in your classroom?

- Yes
  - Great! Here are some additional resources that you may find useful.
    - Provide link or PDF for “What’s Health Got to do with Transition” Curriculum
    - Provide TRAQ 4.1 and instructions for scoring and assessment.
    - Provide Links to: JaxHATS, FloridaHATS and “Envisioning My Future”, 10 Steps to Successful Health Care Transition
    - Provide Handouts by age: 12-14 y/o, 15-17 y/o, 18+

- No
  - Provide Tools for Health Care Transition education in Classroom
If Caseworker:
Is your patient/client in need of:

- Medicaid Information
- Insurance Information
- Self-Advocacy Tools
- SSI Information
- Health Care Provider
- Dental Provider
- Guardianship Information
- Portable Health Summary

Provide Transition tools based on responses.
If Parent or Caregiver:
Do you have a Portable Healthcare Summary for your child?

Parent can choose favorite PHS. Ideally, parent could then answer a series of questions so that the PHS could auto populate, or be taken to the PHS to complete online.
How old is your son, daughter or dependent?

- **12-14 y/o**
  - Provide Checklists appropriate for 12-14 y/o, *Envisioning My Future* Link, and “10 Steps to Successful Health Care Transition”.

- **15-17 y/o**

- **18+ y/o**
If Patient:

1. Ask patient to complete TRAQ 4.1 and provide resources based on answers to those questions.

2. Ask questions related to any health issues, school, work, recreational, or self-advocacy concerns.

3. Provide list of Important Resources based on responses
   - SSI/SSDI
   - Guardianship
   - Medicaid
   - Medicare
   - Self-Advocacy
   - Dental
   - Health Insurance
PARTNER Tool
Assessment of Coalition Networks

- Web-based survey for coalition members that examines organizational linkages needed to achieve strategic objectives

- Help identify strengths and weaknesses of each coalition; areas for improvement

- Results will be disseminated in July/August
Education and Training
Web Site
www.FloridaHATS.org

- Health Services Directory for Young Adults
  - Search by location or type of service
  - 2,000+ listings to-date
  - CMS staff and providers to include description of services; monitor and update as needed

- Calendar

- Tool Box
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 youth and young adults with disabilities or chronic health conditions.

1. Start Early! Begin preparing for transition even when a child is 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. Young people need to learn 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 and health care in one place, including plans for an emergency.

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

5. Maintain wellness. Support good habits that will continue into adulthood! Talk about risky behaviors such as alcohol use and smoking as well as sexuality and relationships.

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

7. Find adult providers. If still in the care of pediatric providers, identify a primary care doctor 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 the young person’s medical conditions and special health care needs for other programs or agencies, as needed.

9. Integrate health care transition activities into 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 to find resources and services.
Become a fan on Facebook and share your health care transition experiences!
Health Insurance Guide for Young Adults

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

Including Those with Chronic Health Conditions or Disabilities

Version 1.0, updated July 2011
Pre-Existing Condition Insurance Plan (PCIP)

**Individual Insurance**

You can purchase a single policy for yourself through one of the health insurance companies listed at the beginning of this section. Or, if you have had a problem getting insurance due to a pre-existing condition, you may qualify for a program called the Pre-Existing Condition Insurance Plan (PCIP). The PCIP was created from the Affordable Care Act of 2010 and is partially funded by the federal government.

<table>
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<tr>
<th>Limits</th>
<th>Eligibility Based on Employment Status</th>
<th>Eligibility Based on Disability/Health Condition</th>
<th>Pre-Existing Condition Exclusion/Other Circumstances</th>
<th>Monthly Premiums</th>
<th>Legislative Mandate</th>
<th>Requires Annual Certification</th>
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</thead>
<tbody>
<tr>
<td>Income</td>
<td>Age</td>
<td>N</td>
<td>N</td>
<td>Y</td>
<td>Y</td>
<td>N</td>
</tr>
</tbody>
</table>

**FACTOID #6:** 87% of young adults polled in the summer of 2009 said that the nation's educators and educational institutions could do more to communicate the basics of health insurance to students to prepare them for graduation.²

The Pre-Existing Condition Insurance Plan (PCIP) was established by the ACA. States could choose to run their own program to cover adults and children with pre-existing conditions or they could elect to have the federal government administer the program. The Government Employees Health Association currently runs PCIP programs in more than 20 states, including Florida. PCIP is a “bridge” program until 2014, when all health insurance companies will be required to cover people of all ages with pre-existing conditions.

Eligibility requirements for the PCIP are that you must:
- be a U.S. citizen or legal resident,
- have been uninsured for at least the last six months, and
- have a pre-existing medical condition.

PCIP benefits include primary and specialty care, hospital care, and prescription drugs. Enrollees can choose from three plan options. As of July 1, 2011, monthly premiums for adults ages 19-32 range from $176-$237. For monthly PCIP premium rates in Florida by the age of an enrollee, go to www.pcin.gov/StatePlans.html#StateInformation.

- No lifetime maximum or cap on the amount paid for care.
- No waiting period.
- Offers “preferred provider” services through a PPO; pays 80% for in-network and 60% for out-of-network services.
- Preventive care is paid at 100%, with no deductible. Included are annual physicals, flu shots, routine mammograms and cancer screenings.
- Out-of-pocket cost for PPO services cannot exceed $5,950 per year; once you reach this limit, services will be paid at 100%. The out-of-pocket limit for non PPO services is $7,000.
- You will pay a high deductible before the PCIP pays for services ($1,000 - $2,500 for in-network providers).
- Your premium may increase as you get older or due to inflation.

Apply for the PCIP online at www.pcin.gov or by phone at 866-717-5826. Applying and enrolling in PCIP is FREE. Do not respond to calls or letters asking you to pay to enroll.
Self-Advocacy for Students with Disabilities

Transition for Students with Disabilities
Advocating for Yourself in Middle School and High School

How to Get What You Need

You should always be able to have the accommodations you need in school for your disability or medical needs. Sometimes it takes some extra effort to get what you need. Having a disability doesn’t mean you can’t do as well as the other kids in school. You have the same right as others to succeed! By law, every school has a process - or a set way - for you to talk to teachers and others about what you need. Sometimes this is addressed through a formal plan called an Individual Educational Plan (IEP) or a 504 plan.

Step 1: Evaluate what you need.
Sit down with your parents and decide what accommodations you need based on your disability, like extra time on tests, a note taker, or two sets of books. Only pick accommodations that are necessary for your disability. For example, if you know you don’t need a program on your computer that reads books to you, don’t ask for it. People with different disabilities need different things. Using fewer accommodations while in school will help you prepare for postsecondary education or training, where fewer accommodations are allowed.

Step 2: Find a helpful resource at school.
This could be a teacher, vice-principal, transition specialist, or counselor who is willing to work with you and make sure you get what you need. Ask other kids who get accommodations at school what works for them, or talk to the principal about what is available. Once you find a helpful resource, have a meeting with that person and see what they can do to help you advocate for yourself.

Step 3: Talk to your teachers.
Try to have a meeting that includes all your teachers, your parents, transition specialist, and other people who help you at school. With the help of your parents and others, you can advocate for yourself. Teachers have overall authority in the classroom, so it’s important that they understand your needs. If a meeting is not possible, have your parents write a letter. If you are in high school, talk to your teachers and let them know that they can contact your parents with any questions. If a teacher is unwilling to work with you, talk to someone in school administration - like the principal or Director of Exceptional Student Education (ESE) - about the problem. Teachers must be fair to all students.

Step 4: Have a follow up meeting.
Several times during the school year you should stop by to see your transition specialist or resource staff, and let them know how everything is going. Halfway through the year you should have a meeting with your parents and resource staff, and try to have one teacher present to talk about what is working for you and what isn’t.

Other forms of advocating for yourself and getting what you need:
- Know about your disability so you can explain it to teachers or others, if needed.
- Your health information is confidential; it’s your decision about how much you want to share. Teachers and other school personnel are required to respect a student’s privacy.
- There’s a difference sometimes between advocating for what you want and advocating for what you need to get schoolwork done. If you’re not sure, ask a friend, parent or teacher if they think it is something you need in order to get schoolwork done. You can still advocate for what you want in other areas but it may make more sense to do it at a different time or with different people.
- Ask for extended time on standardized tests, if needed - including the SAT, ACT and AP tests. Know that there is a formal process for getting accommodations on many standardized tests that will require you to make requests weeks to months in advance.
- If you feel that a student doesn’t understand your disability, try talking to them and see if you can open their eyes to the wonderful person you are. If that doesn’t work, don’t be afraid to talk to a teacher or administrator (such as a principal or Director of ESE) about it.
- If you feel you are being mistreated by any adult, go to someone you trust IMMEDIATELY.
- There are other kids who are going through the same things, so try not to be afraid to express yourself.
- Be proud of who you are...always!
Preparing for IEP Meetings

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

Visit www.FloridaHATS.org

What You Need to Know
If you're a parent of one of the 6 million children with disabilities in the U.S., you're undoubtedly aware of the Individualized 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.

For many parents, the annual IEP meeting can be a difficult and stressful encounter. You may have trouble making your child's case because you feel intimidated by school administrators and experts. There may be obstacles beyond your control, such as a teacher shortage, inadequate funding, or limited program options. While the process can seem overwhelming to a parent, it doesn't need to be this way.

You don't need to be a special education expert or a lawyer 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 tenth IEP - will benefit from reviewing the following steps well in advance of the IEP meeting.

Step 1: Understand your child's legal rights to special education.
Your school district is required by IDEA to give you copies of special education statutes, regulations and policies. Read these carefully, keeping 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.
Become 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 for children with learning disabilities or a private school for deaf children.
- Goals and Objectives - the general academic, linguistic, social, 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 - the developmental, corrective and other supportive services necessary to facilitate your child's placement in a regular class or to allow your child to benefit from special education. Examples include a one-to-one aide in the classroom, speech therapy or transportation to and from school.
- Transition Services - any supportive services addressing vocational and advanced placement needs of children age 14 and older, including post-secondary independent living.
- Other Educational Components - anything else your child needs to succeed, such as particular curricula and teaching methods.

Step 3: Become an expert about your child's educational performance and needs.
Keep in regular contact with your child's teacher and other school representatives, and gather opinions from professionals who know your child. Get copies of everything in your child's school file, including assessments, testing data and written comments from teachers. Figure out what each item means and think about whether you can use it to demonstrate your child's need for a particular program, service, or methodology.

Step 4: Know your options.
Gather information about various programs and services within your school district as well as those outside of it that may be appropriate for your child. Talk to your child's teacher, professionals who have evaluated your child, the district special education administrator, and other parents. Visit as many of these programs as you can before the IEP meeting.
YSHCN in DJJ System

- Interagency workgroup explored ways to care and outcomes for YSHCN in DJJ system
- Strengthen communication and linkages between CMS and DJJ
- Developed parent/caregiver guide to answer questions about DJJ systems and procedures
  - Web-based; Spanish translation
A Guide to the Florida Juvenile Justice System for Parents of Youth with Disabilities or Chronic Health Conditions

Developed by FloridaHATS and Project 10 in partnership with Florida Department of Juvenile Justice, Florida Department of Education, and Florida Department of Health, Children’s Medical Services

June 2012

www.floridahats.org/?page_id=2338
Health Care Provider Web-Based Training

- 4 free CME/CEUs for physicians, nurses, social workers, psychologists, dentists, etc., at www.aheceducation.com

- May 2010 launch
  - 125 participants to-date; brochure recently mailed to FQHCs
  - Avg. 4+ satisfaction rating (1 low – 5 high)

Recertified for 2 years (until May 2014)
  - Revised introduction
Training for Health Care Professionals

Produced by
The Institute for Child Health Policy, University of Florida
Florida Health and Transition Services (FloridaHATS)
University of South Florida
Children’s Medical Services, Florida Department of Health

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?

www.aheceducation.com
Educator Training

- 6 in-service hours for secondary ESE teachers, administrators, transition specialists
- Web-based
- Piloted with Sarasota Public Schools
- Expected launch in 2012
Health Care Transition Training Program for Educators

Fact: 16% of youth in Florida have special health needs.

Fact: Only 1/3 of these youth are prepared to get needed health care when they become adults.

Fact: Good health and securing a good job go hand in hand.

Fact: As an educator in Florida, you can help address this problem.

The Health Care Transition Training Program is comprised of three one-hour video modules and three homework assignments. Each video module addresses 4 or 5 issues, making it easy to watch short segments as time permits. For each module, learners can select from a list homework assignments which provide an opportunity to apply the information from the videos to the school setting.

A Certificate of Completion for this 6-hour course (3 hours of video-lecture plus 3 hours of homework) will be issued upon successful completion of the training program. Check with your school district to receive 6 in-service points for the HCT Training Program.

Training author, John Reiss, PhD, is an Associate Professor at the Institute for Child Health Policy, University of Florida.

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

Training Program Overview

- Learn how to partner more effectively with health care professionals.
- Learn how health conditions impact classroom learning, and what you can do to improve student learning.
- See how “health transition” can be integrated into student goals and activities.

Contents Include:

I. Introduction
II. What Is Health Care Transition?
III. Health Care Transition: An Emerging Issue
IV. Transition Stages
V. Video: “Jim’s Story”
VI. Promoting CSHCN’s Optimal Learning in the School Setting
VII. Promising Practices in Health Care Transition
VIII. Transition and Health Insurance
IX. Legal Rights of 18 Year Olds
X. Incorporating Health Care Transition in School-based Transition Plan Development and Implementation
XI. Video: “College and Beyond”
XII. Health Care Transition Planning Guides
XIII. Perspectives from Youth and Adults

transition.mchtraining.net

School nurses, psychologists, social workers, mental health counselors, and other health care professionals can earn up to 4 free CEU/CME hours at www.aheceducation.com.

For more information, visit www.FloridaHATS.org.
UF Graduate Certificate in Education and HCT

- Graduate level, online certificate
- 12 credit hours (can be completed in 1 year)
- To learn more, visit: http://education.ufl.edu/education-healthcare-transition/
Medical Advisory Committee (MAC) Medical Education Initiatives
Transitional Care Modules

- Transitional Care for Patients with Down Syndrome module developed by John McCormick, USF
  - Targeted to Med-Peds residents and adult physicians
  - First in series of selected childhood onset diseases or conditions; focus on disease process rather than socio/behavioral aspects of transition
  - Opportunity for other providers to collaborate with Dr. McCormick in module development
  - Module(s) to be posted on FloridaHATS web site
HCT in Electronic Health Records

- USF pilot intervention that uses EHR in training Peds and Med-Peds residents about HCT and new clinical guidelines
  - Address preparation for transition to an adult care model for all adolescents
  - Transition-related discussions to be included in all well-child visits starting at age 12
  - Enhanced preparation/planning for YSHCN
  - Use standardized tools
Florida Physician Education in Developmental Disabilities (PEDD)

- Curriculum targeted to practicing family physicians and medical residents
- Web-based modules to launch July 2012
  - 12 content areas; 1 hour modules
  - Developed, narrated by Florida experts
  - HCT module in development
- Partner with Florida Association of Family Physicians to recruit participants
Partnership with Medical Associations

- Florida Pediatric Society (FPS) and Florida Medical Association (FMA)
  - HCT Workshop at 2012 FMA annual conference in July, Boca Raton
  - Legislative and advocacy support
Florida Family Physician

- Articles on both FloridaHATS and PEDD in June issue
  - Quarterly journal, 4,000 circulation
  - Special theme issue “Caring for Patients with Developmental Disabilities”

- Thanks to FDDC for facilitating!
Florida Family Physician
June 2012

Florida Health and Transition Care: Bridging the Gap, by Florida Physicians in Transitional Care (GLPCVT) and Florida Department of Health in the Florida Department of Health in the Florida Department of Health (FDOH) in Florida. Florida Department of Health

Clinical Guidelines for Transition Care
Florida CT quiz (available at: http://epubs.democratprinting.com/publication/?i=114953

Caring for Patients with Developmental Disabilities

Table 1. Five Elements of Health Care and Developmental Disabilities


http://epubs.democratprinting.com/publication/?i=114953
National Updates
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 on:
  - Changing health needs in adulthood
  - Transition to adult health provider
  - Insurance needs into adulthood
  - Youth encouraged to take increased responsibility for care
MCHB Core Outcome #6: CSHCN age 12-17 years who receive services needed for transition to adult health care, work and independence

CSHCN age 12-17 years only

Nationwide vs. Florida
Outcome successfully achieved

2009-2010 NS-CSHCN Data Resource Center for Child and Adolescent Health
Got Transition?
National Health Care Transition Center

- National and state resources at www.gottransition.org
- Provider Learning Collaboratives
  - Quality improvement initiative for pediatric and adult providers
- Radio Broadcast Series
  - Youth Leadership
  - School IEPs
  - College
  - Decision-Making Alternatives
Legislation and Advocacy
2012 Legislative Session Recap

- Key provisions
  - Extend care coordination support for CMS patients to age 26
  - Recognize Florida HATS as the state office for HCT
- Sponsors: Wise/Storms in Senate, Logan/Grant in House
- Passed in Senate committees, died in House (not read in committee)
- Age extension, potential financial implications raised concerns in House
**SB 282/HB 279**

**Florida Health and Transition Services**

Legislation is needed to provide critical link between pediatric and adult health care for vulnerable young adults.

**Problem**

Youth & young adults with childhood chronic health conditions or disabilities often struggle to access adult medical care, resulting in disease complications, increased emergency room visits and hospitalizations, and development of secondary disabling conditions.

**Background**

- There are over 600,000 youth & young adults with special health care needs age 15-26 living in Florida.
- Each year, approximately 50,000 teenagers with special needs age out of children's services and programs.
- The transition from adolescence to adulthood is problematic because these patients often cannot find doctors who are qualified and willing to treat them. In fact, in Florida, less than 34% receive needed services statewide, and only 1% in rural areas receive needed transition services.
- Without a medical home, these young adults are at greater risk for acute episodes or death due to their primary condition, or development of secondary disabling conditions – factors that impact ability to work and increase costs to families and communities.
- CMS currently cannot provide care coordination services to eligible client ages 21+, at a time when health benefits often change, and clients need more assistance in learning to navigate the adult health care system.
- In 2009, legislators established a State Task Force to assess the need for healthcare transition services. The legislation would ensure many of the Task Force’s recommendations to improve transition in Florida.
- The bill would build on the success of a model program – John H. Bartels Health Care Transitions Program – that has reduced ER visits by 30% since it was established in Jacksonville in 2008.
- Since submitting the legislative report, the Task Force has continued to meet and begin implementation of recommendations. Activities include organizing participants, creating community-based coalitions to build local systems of transitional care, creating an insurance guide for young adults, developing web-based training for health care providers and educators, and creating an online locator of resources for both care providers and families. See [www.floridahealthtransition.com](http://www.floridahealthtransition.com).

**Key Provisions**

- Extends authority of Children’s Medical Services (CMS) to provide care coordination support for youth & young adults with special health care needs age 15-26 (previously authorized to age 21).
- Identifies Florida Health and Transition Services (FloridaHATS) as the program within CMS to help community-organized local service systems that link pediatric and adult health care, and to develop plans for regional health and transition services programs.
- Clearly defines the locus of responsibility and components needed to build community-based service systems.
- Provides for consumer education about health care transition.
- Provides for professional training to increase provider capacity.
- Does NOT provide payment for services.
- Does NOT require a legislative budget appropriation.

**Enacted By**

Florida Medical Association
Florida Pediatric Society
Florida Developmental Disabilities Council
Florida Association of Children’s Hospitals

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**4-Page Policy Brief**

**Health Policy Brief SB 282/HB 279**

Legislation needed to provide critical link between pediatric and adult health care for vulnerable young adults.

**What’s the Issue?**

Youth and young adults with childhood chronic health conditions or disabilities often struggle to access adult medical care, resulting in increased disease complications, increased emergency room visits and hospitalizations, and development of secondary disabling conditions.

**What’s the Proposed Policy Action?**

- Authorize Florida Children’s Medical Services to support young adults with special health care needs up to age 26
- Define the locus of responsibility and components needed to build service systems that link pediatric and adult health care.
- Through Florida Health and Transition Services, provide assistance to communities in organizing local systems of health care.
- Provide consumer education about transition from pediatric to adult health care.
- Provide professional training to increase provider capacity in caring for young people with childhood onset chronic disease and disability.

**What’s the Background?**

The number of youth and young adults with chronic medical conditions and disabilities has increased dramatically over the last 4 decades. In the U.S., approximately 5 million young adults ages 18-26 have special health care needs. Each year, almost 30,000 young Floridians with childhood onset conditions become adults. Advances in medical care have allowed this population to survive; however, our current health care system does not adequately support them in adulthood.

**50,000**

Ridians with special needs become adults each year.

Today, more adults than children are living with congenital heart disease and cerebral palsy. Without age-appropriate, continuous medical care, this population is more likely to experience disease complications and to develop secondary disabling conditions – factors that impact ability to work and increase costs to individuals, families, and communities.
2013 Legislative Strategies

- Stratify CMS enrollees based on need for extended care coordination services
  - Explore ways to identify most vulnerable patients
  - Target cohort of patients to receive care coordination up to age 26

- Consider proposal for pilot study in 3 coalition communities
  - CMS conducts standardized readiness assessment to identify patients who are not ready for an adult model of care.
Looking Forward: What You Can Do

- Identify potential bill sponsors, e.g., legislators that have a family member with a disability or a special interest in health

- Disseminate information about Florida HATS
  - Downloadable materials on website
  - Contact Janet Hess for hard copies

- Expand resource directory to include all adult providers in your community that serve young people with special health care needs
Thank you for joining us!