Health Care Transition
and the DJJ Population

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Agenda

- What is Health Care Transition?
- What Are the Issues?
- How Are We Doing?
- Supporting HCT in DJJ System
- Additional Resources and Training
- Contacts
What is Health Care Transition?
Definition: HCT

- Health care transition is the “purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered care to an adult-oriented care system.”

Source: Blum et al., 1993
Definition: CYSHCN

- 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
Changing Epidemiology of Childhood or Congenital Conditions

**Congenital Heart Disease**
- ~800,000 adults in the U.S. have CHD
  - 419,000 with moderate to severe complexity
  - At risk for re-operation, premature mortality
- More adults than children

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

United Cerebral Palsy website (www.ucp.org/ucp_generaldoc.cfm/1/9/37/37-37/447)
Sickle Cell Disease

Significance

- Approximately 17% of children and youth have special health care needs

- Less likely to:
  - finish high school
  - pursue postsecondary education
  - find a job
  - live independently

- 3x more likely to live on income < $15,000

Source: USDHHS, 2001
Significance

- Youth with vs without special health care needs
  - 41% vs 32% report being engaged in high risk behaviors (e.g., smoking, drug use) within the past month
  - 39% vs 18% report symptoms of depression
  - Among youth ages 14-17 on SSI:
    - 35-50% drop out of high school
    - 32% end up in the Juvenile Justice System

YSHCN in Florida’s DJJ System

- Many have chronic medical conditions such as diabetes, hypertension, hemophilia, sickle cell disease, renal failure, etc. as well as serious dental disease; a subset are developmentally disabled.

- Some have not accessed medical care prior to entering DJJ facilities and new diseases are discovered while they are in custody.

- Over 65% have a mental illness or substance abuse issue.

- A significant number also have experienced severe childhood trauma (physical, sexual, emotional abuse) which impacts their behavior and treatment needs.

Florida Department of Juvenile Justice Web site, www.djj.state.fl.us/HealthServices/index.html
Why is HCT Important?

“A poor transition in health care can threaten health and undermine other transitions, for example in education, work, social relationships, and independent living.”

Source: Institute of Medicine, 2007
What Are the Issues?
What Are the Issues?

- Professional culture and traditions

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<th><strong>Pediatricians</strong></th>
<th><strong>Adult Physicians</strong></th>
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<td>Disease Focus</td>
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What Are the Issues?

- Changing role of youth
  - Learning about health insurance, legal rights, self-care, health management skills
  - Disconnected expectations

- Capacity and training: Availability and quality of adult providers who are
  - Trained in pediatric onset conditions
  - Willing to take primary responsibility for care
What Are the Issues?

- Communication
  - Among providers
  - Between adult provider and youth
  - Information about resources and adult services

- Service fragmentation
  - Lack of systematic transfer of records and co-management of care during transition
  - Minimal case management in adult practices
  - Linkages to community-based adult services
What Are the Issues?

- Adequate health insurance after age 18
  - Aging out of health care plans/services (private insurance, state Title V, SCHIP) at age 19 or 21
  - Benefits in temporary jobs often limited, unavailable, or high premiums
  - Desire to work and be independent may jeopardize dependent status needed to remain on health plan
  - Increased salary may lower/eliminate SSI payments
  - Limited benefits provided in adult Medicaid package

- Provider knowledge of reimbursement guidelines
What Are the Issues?

- Other systemic barriers
  - Employment opportunities
  - Transportation
  - Limited assistance for adults with disabilities
    - Fewer publicly funded programs
    - Stricter eligibility criteria
    - Increased financial burden
    - Termination of childhood support systems
What Are the Issues?
A Framework for HCT

- Ongoing access to age and disease-appropriate primary and specialty care providers
- Access to uninterrupted, affordable health insurance
- Development of disease self-management skills
- Access to age appropriate educational and vocational opportunities to allow economic self-sufficiency

How Are We Doing in Florida?

Outcome #6: CSHCN ages 12-17 who receive services needed for transition to adult health care, work at independence

Florida vs. Nationwide

Improving HCT in Florida: 2008-2010

- Developed a statewide plan for health care transition, including strategies and best practices to increase access

- Established a new program in the Department of Health/CMS to implement the plan: Florida Health and Transition Services (FloridaHATS)

- Organized pilot regional HCT coalitions in Hillsborough County, NE Florida, and the Panhandle area

- Created web site and online tool box for consumers and professionals: [www.FloridaHATS.org](http://www.FloridaHATS.org)
Improving HCT in Florida: 2008-2010

- Created health insurance guide for young adults ages 18-30
  - Provides range of health care financing options that are available, helpful tips and guidance, resources, glossary
  - Online and in print; Spanish and Creole versions also online

- Web-based cross-disciplinary training for professionals
  - Free CME/CEUs for physicians, nurses, social workers, dieticians, psychologists, mental health workers, respiratory therapists, dentists
  - Available through Gulfcoast AHEC at www.aheceducation.com

- Web-based training for educators
  - Targeted to Secondary ESE teachers, transition specialists
  - Launch in Spring 2011
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
Are you a professional looking for FREE continuing education credits on a health care topic that really matters to your adolescent and young adult patients and their families? 

Health Care Transition Training Program

Training Program Overview

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

Contents of Module 1:
- Introduction by Susan General
- Transitioning Successful From Pediatric to Adult Health Care
- What is Health Care Transition?
- ICT as Emerging Issue
- Transition Stages and Issues
- "First Story"
- Policies and Practices of Health Care Providers and Facilities
- Pediatric and Adult Care: Two Different Cultures
- Transition and Health Insurance
- Transition in Education
- Transition in Vocational Rehabilitation
- Legal Rights of 16 Year-Olds

Contents of Module 2:
- College and Beyond
- Promoting Practices
- Developmental Model of Health Care and Child Family Professional Relationships
- Therapeutic Transition of Care Relationships
- Health Care Transition Planning Guide
- Transition Resources
- Perspectives From Youth and Young Adults for Healthy and Healthcare Providers
- Transition Resources at the Institute for Child Health Policy, University of Florida

Accreditation

The four-hour-long Health Care Transition Training Program is broken down into two two-hour modules. The accreditation statements below apply to each module for a total of four contact hours.

Module 1:

This activity has been planned and implemented in accordance with the Essential Areas and Policies of the Accreditation Council for Continuing Medical Education through the joint sponsorship of the Florida AHEC Network, the University of Florida, the University of South Florida, the Florida Department of Health, Children's Medical Services and the Florida Developmental Disabilities Council, Inc. The Florida AHEC Network is accredited by the Florida Medical Association to provide continuing medical education for physicians. The Florida AHEC Network designates this educational activity for a maximum of 2.0 AMA PRA Category 1 Credits™ for each module. Each physician should claim credit commensurate with the extent of his or her participation in the activity.

Module 2:

LORI L. CHAPMAN, MD, Florida North Area Health Education Center, Inc., is a Florida Board of Nurse-Approved provider of continuing education. CE Broker Provider #7560264. This program meets the requirements for up to 2.0 total contact hours for each module.

LESLIE GRENSKE, RN, Florida South Area Health Education Center, Inc., is a Florida Board of Nursing approved provider of continuing education. CE Broker Provider #7560264. This program meets the requirements for up to 2.0 total contact hours for two modules.

DataSafe - Newfoundland AHEC, is a Florida Board of Dentistry approved provider of continuing dental education. CE Broker Provider #7560264. This program meets the requirements for up to 2.0 total contact hours for each module.

This program is compliant with Florida Rules of Practice, P.D. 20-21, 7.36 and 2.36. See above.

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

Introductions by
Dr. Ann Vizcarra
Director, Department of Health

www.aheceducation.com
Improving HCT in Florida: 2008-2010

- Developed program brochure and “10 Steps to Successful Health Care Transition” insert
  - Promote educational/training products for consumers and professionals
  - Printed English version; Spanish and Creole versions on web site

- Facebook Page

- Health Services Directory for Young Adults
  - Search online by location and type of service at www.FloridaHATS.org
10 Steps to Successful Health Care Transition

Visit www.FloridaHATS.org
to view in large print

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

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

Visit www.FloridaHATS.org to find resources and services. Become a fan on Facebook and share your health care transition experiences!
New Affordable Care Act
Impact on Youth and Young Adults

Effective in 2010:

- Eliminates exclusions in covering pre-existing conditions for children
- Young adults up to age 26 can enroll in parents’ private insurance plan, regardless of marital status or living situation, if they aren’t eligible for any other employer-sponsored plan (the last provision is only until 2014)
- Prevent carriers from imposing lifetime limits and place restrictions on annual limits on benefits (in 2014, annual limits banned)

Effective in 2014:

- Requires coverage of oral and vision needs for children
- Extends Medicaid coverage up to age 26 to foster care children
- Expands Medicaid eligibility to all legal residents up to 133% FPL
- Creates state-based health insurance Exchanges to provide more private options
  - Options for cost-sharing subsidies, caps on out-of-pocket expenditures

Tools, Tips & Resources
Florida’s clearinghouse for health care transition information:
www.FloridaHATS.org
Download videos, CDs, brochures, workbooks, checklists: http://hctransitions.ichp.ufl.edu/
National clearinghouse for health care transition information: www.gottransition.org
Online training module for youth and families:
http://hctransitions.ichp.ufl.edu/ddcouncil

Statewide directory of CMS Network service providers:
www.cmskidsproviders.com/eis
Florida Department of Education’s Project 10 provides a regional transition service directory and other ESE resources:

www.project10.info/DistrictFlorida.php
The Florida Bar

“Legal Guide for New Adults”

www.floridabar.org/tfb/TFBConsm.nsf/0/34557641d4c2f7c885256b2f006c5753!OpenDocument&Click=

Information and assistance about guardian advocacy for persons with developmental disabilities

www.centerforguardianadvocacy.com
Supporting YSHCN in the DJJ System
What You Can Do to Support HCT

- Encourage self-determination and independence in managing health care
  - Talking to doctors, filling prescriptions, taking medication, scheduling appointments, decision-making, etc

- Help YSCHN identify potential adult health care providers

- Help YSHCN identify and access adult health insurance coverage

- Help YSHCN explore publicly funded benefits they may qualify for in adulthood based on their needs and conditions(s)

- Coordinate linkages to community-based adult services and supports, including mental health
What You Can Do to Support HCT

- Assist YSHCN in developing a health care summary to carry with them at all times
- Work with schools to include HCT goals and activities in IEP and 504 Plans
- Review legal rights and responsibilities at age 18
- Discuss guardianship or decision-making options, if needed
- Encourage positive social networking experiences with other teens who have similar life challenges
Coalitions of youth, families, and providers in Hillsborough County, NE Florida, and the Panhandle are dedicated to improving health care transition in their service areas.

Developed local action plans in 2010; currently beginning implementation.

Anyone who is interested can join!

Meeting information, updates, and local resources are posted under “Regional Coalitions” at www.FloridaHATS.org.
State-Level Workgroup

- Establish better communication between DJJ and Children’s Medical Services (CMS)
- Explore how to identify YSHCN in DJJ as soon as they enter the system, and notify their CMS providers
- Educate CMS Care Coordinators about DJJ policies and procedures, and visa versa
- Educate YSHCN and their families about what to expect in the DJJ system
  - Develop materials to disseminate via CMS, school system, and other agencies
- Repository of information from the Workgroup located on the FloridaHATS web site
- Let us know about issues and concerns that you’d like the Workgroup to address
Additional HCT Training

- Learn more about what you can do to help your patients transition to appropriate adult health care
- Receive 4 free contact hours
- Go to www.aheceducation.com
Contacts

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