Building a State
Health Care Transition Plan:
The Florida Experience

October 18, 2012
Presenters

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Disclosures: Janet Hess, David Wood and John Reiss have no personal financial relationships with commercial interests to disclose.
Agenda

- Legislation
- State Strategic Plan
- Systems-Building through Regional Coalitions
- Plan Implementation: 2009-2012
Legislation
Florida SB 988 / HB 793

- Florida advocates identified a legislative champion, Senator Stephen Wise
  - Senator Wise supported 2004 development of JaxHATS, a transition clinic in Jacksonville
  - Proposed bill to assess need for health care transition (HCT) services in Florida
- SB 988/ HB 793 passed in 2008 session
Florida SB 988 / HB 793

- Mandate to assemble a multi-agency Task Force and obtain input from stakeholders, including YSHCN

  - Chaired by Title V Director, Children’s Medical Services (CMS)

  - Participation of key agency leaders required:
    - Department of Education
    - Department of Children and Families
    - Agency for Health Care Administration
    - Agency for Persons with Disabilities
    - Division of Vocational Rehabilitation
Florida SB 988 / HB 793

- Assess and document need
- Identify strategies/best practices
- Present range of different models
  - To accommodate geographic and cultural diversity
  - To adapt to local needs, health system
  - Integrate with education, vocation, independent living programs
- Identify existing and potential funding sources
- Submit report to Governor, Legislature by 1/1/09
Needs Assessment

- Financial support from Florida Developmental Disabilities Council (FDDC)
- Hired Project Facilitator
- Task Force
  - 14 appointees plus 21 additional stakeholders; 35-member group
- 2 face-to-face meetings of Task Force
- Created project web site, email distribution list, teleconference venue
Needs Assessment

- 3 Subcommittees
  - Education & Training
  - Financing
  - Services & Models of Care

- 13 Subcommittee teleconferences
  (4-5 per subcommittee)

- Compiled personal stories from young adults, families, providers
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. Cham, M.D., FAAP, Chair
Health Care Transition Services
Task Force
January 1, 2000

Legislative Report
Legislative Report

- 38-page report
- 16 recommendations
- Stratified strategies that could be accomplished with few additional resources versus those requiring more significant financial support
- Disseminated print copies
- Positive response from legislators, agencies
Task Force Challenges

- **Timeframe**
  - Short period of time to develop legislative report

- **Difficulty engaging YSHCN**
  - Amount of time required
  - Meeting schedule conflicts

- Identifying participant availability for large group meetings

- Diverse group of participants had limited opportunities for face-to-face networking and relationship-building
Strategic Plan
Plan Development

- Refined and formatted Legislative Report
- Developed Mission, Vision, Values
- 4 overarching Goals with corresponding Objectives
  - Services and Models of Care
  - Health Care Financing
  - Education and Training
  - Infrastructure
Key Strategies

- Services and Models of Care
  - Establish a state Office of HCT
    - Locate within CMS
    - Provide oversight and technical assistance in plan implementation
  - Organize regional public/private HCT coalitions
  - Develop and monitor performance measure at state and local levels
Key Strategies

- Health Care Financing
  - Create an Insurance Resource Guide for YSHCN
  - Work with insurers to develop policies that support medical homes, care coordination, co-management of YSHCN
  - Advocate for a Medicaid Buy-In program
  - Advocate for insurance payments to reflect the time and resources required for appropriate care of YSHCN
Key Strategies

- **Education and Training**
  - Disseminate HCT educational materials to YSHCN, families, and providers
  - Provide training for professionals (CME/CE credit)
  - Create an online toolkit and clearinghouse of information
Key Strategies

- Infrastructure
  - Secure legislation and funding to support the Office of HCT in building regional service systems
  - Establish operational and oversight systems for the Office
Resulting Structure

- Established Florida Health and Transition Services (FloridaHATS) within CMS
  - Funded by CMS
  - Contracted Staff
    - Project Director
    - Medical Director
- Collaborative Partners
  - FDDC
  - Institute for Child Health Policy-UF
  - Medical Advisory Committee
  - Task Force members
Systems-Building through Regional Coalitions
A Public Health Approach

Vertical and Horizontal Integration Model for Health Care Transition in Florida

- Federal
  - MCHB Title V
  - HP2010

- State
  - DOH/CMS
  - FDDC
  - Children & Youth Cabinet
  - Project 10

- Community
  - Primary & Specialty Care
  - Hospitals
  - Clinics
  - FQHCs
  - CHD
  - CIL
  - Mental Health
  - Social Services
  - School District

- Family
  - Y/YA
  - Parents
  - Caregivers
A Public Health Approach

- Use a collaborative community planning model to develop local systems of transitional care
- Oversight and technical assistance from FloridaHATS
- 3 pilot sites – mix of urban and rural
  - Tampa-Hillsborough County: HillsboroughHATS
  - Jacksonville-Duval County: Jacksonville HATS
  - Pensacola/Panama City Area: PanhandleHATS
Task Force adapted MAPP planning process (Mobilizing for Action Through Planning and Partnerships)

Developed Strategic Planning Guide for Regional Coalitions

- Visioning
- Assessments
- Community Themes & Strengths
- Health Care Transition System Assessment
- Youth/Young Adult Health Status Assessment
  - Provided multi-source, county-level data report
- Forces of Change Assessment
- Identify Strategic Issues
- Formulate Goals and Strategies
### Participant Worksheet

Use this worksheet to help you identify participants for your Coalition’s strategic planning process. Be sure to include both pediatric and adult-based health service providers in your planning group, and target 15-20 committed members.

<table>
<thead>
<tr>
<th>Organizations</th>
<th>Pediatric</th>
<th>Adult-Based</th>
<th>Notes</th>
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<tbody>
<tr>
<td>Primary Care</td>
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<td>(Are there large group practices?)</td>
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<td>Specialty Care</td>
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<td>Hospitals</td>
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<tr>
<td>Mental Health Organizations</td>
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<td>Professional Associations, Collaborations</td>
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<td>OAD Area/Region</td>
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<td>Nurses/Medical Director</td>
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<td>Funding Agency and Families</td>
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<td>County Health Department</td>
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<td>Community Health Centers (Payer Qualifying Health Centers)</td>
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<td>Free/Low Cost Clinics (We Care, Migrant/Indigent Care)</td>
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<td>Center for Independent Living</td>
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<td>Project or District Representative (Education)</td>
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<td>Funders and Policy Makers</td>
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<td>Public/Private Health Insurance, Local Children’s Services Council; Grants, Legislatives</td>
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<td>Advocacy and/or Condition-Specific Organizations</td>
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<td>Vocational Rehabilitation</td>
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<td>Military</td>
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<td>Community-Based Care (Foster Care)</td>
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<td>Agency for Persons with Disabilities</td>
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<tr>
<td>Other Potential Partners: Faith-based</td>
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<td>Universities/Colleges</td>
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<td>Transportation</td>
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<td>Chamber of Commerce</td>
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<td>Legal</td>
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<td>Family Support Centers</td>
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<tr>
<td>Information &amp; Referral Programs (2-1-1)</td>
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</tbody>
</table>
MAPP

- Hired MAPP facilitator for each pilot site
- 20-30 member coalition representing health care (pediatric and adult care), developmental disabilities, hospitals, universities, advocacy groups, YSHCN and families
- Met monthly from over 5 months
- Working documents posted on web site
- Local strategic plans developed, action steps prioritized
Coalition Action Plans

- Support state goals
- Address unique needs and assets in regions

Common themes:
- Increase awareness of health care transition in the community
- Develop local resource directory
- Promote transition services in the medical home
- Identify and engage adult providers
- Promote communication across pediatric and adult providers
- Outreach and education for families and youth
- Development of care coordination across transition
- Triage services based on the youth and families' health care and social needs
- Engage community leaders, politicians, and funders
- Raise additional resources
HillsboroughHATS Coalition Action Plan

Vision

The HillsboroughHATS Regional Coalition works toward improving the transition process for youth and young adults with chronic-complex healthcare needs in the 21st century. Through enhanced patient and family-centered goals, the coalition will work to support a continuum of care, while improving accessibility, throughout the patients' life span. With the use of education and training, adequate funding and advanced technology, it is our goal to enhance the patient’s and families’ quality of life for many years to come.

Strategies and Action Steps

Strategic Issue 1: What is needed to ensure a successful healthcare transition for Y/YA with complex health and behavioral health needs as they transition from a pediatric to adult system of care?

Objective 1.1: Identify all potential health care and support service resources related to transition and assets that serve young adults with disabilities or health care needs as a first priority.

<table>
<thead>
<tr>
<th>Activity/Action Step</th>
<th>Responsibility</th>
<th>Resources/Partners Needed</th>
<th>Status to Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.1.1 Identify existing facilities and providers such as community health centers, health departments, academic centers, subspecialty centers, through interviews with key informants.</td>
<td>Services and Cross-System Relationship Building Workgroup</td>
<td>Statewide web-based service directory operational in Dec 2010. Individuals to conduct interviews and compile information.</td>
<td>Health Services Directory for Young Adults launched on <a href="http://www.FloridaHATS.org">www.FloridaHATS.org</a> in Dec 2010; new listings can be submitted by CMS staff or directly by providers.</td>
</tr>
<tr>
<td>1.1.2 Identify community support services such as voc rehab, respite care providers, metro charities, CMS support at work, subspecialty centers.</td>
<td></td>
<td>Individuals to compile information; Self Reliance Center for Independent Living</td>
<td>Identified multiple local and statewide resources: 2-1-1, FloridaHATS Health Services Directory, Project 10 Directory, Special Olympics Directory</td>
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<tr>
<td>1.1.3 Develop community-wide system to provide information and guidance to providers about available services</td>
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<td>CMS</td>
<td>A detailed material dissemination plan has been developed. The workgroup plans to educate providers by mail, electronic communication, meeting/conference presentations (see 3.1.2 below) and delivering HATS materials to practices.</td>
</tr>
</tbody>
</table>
Lessons Learned

- A few lessons learned from planning process:
  - Positive experience for most stakeholders
  - Need a skilled MAPP facilitator
  - Allow at least 6 months for planning – there’s a steep learning curve for most participants!
  - Extensive time commitment for planning can make it difficult to engage physicians and YSHCN
  - Critical to have a coordinator to manage implementation
Coalition Activities

- Hired a coordinator for each coalition
- Organized workgroups
- Combination of face-to-face and teleconference meetings
- Education and training, advocacy, service models
  - Community events
  - School, social service linkages
  - Localized materials
  - Partner with hospitals, medical/nursing associations
  - Grand Rounds presentations
PanhandleHATS

For more information, contact Pat Dunn Cole, Coalition Coordinator at PanhandleHATS@bellsouth.net or (850) 438-6644. See Fact Sheet.

Next Meeting

See Calendar

Coalition Meeting Documents

- 5-24-12 Meeting Minutes
- 12-8-11 Meeting Minutes
- 9-22-2011 Meeting Minutes
- 4-27-11 Meeting Minutes
- 2-24-11 Meeting Minutes
- 2-24-11 Meeting Presentation
- 1-19-11 Meeting Minutes
- 1-19-11 Meeting Presentation
- PanhandleHATS Action Plan (draft)
- 5-8-10 Meeting Minutes
- 4-12-10 Meeting Minutes
- 3-8-10 Meeting Minutes
- 2-22-10 Meeting Minutes
- 1-25-10 Meeting Minutes
- PanhandleHATS Fact Sheet

Steering Committee Meeting Minutes

- 8-10-11 Meeting Minutes
- 6-29-11 Meeting Minutes
- 12-11-09 Meeting Minutes

Community Resources

- CMS Transition Algorithm (draft 4-25-11)
- Bay County Resource Guide
- Community-Based Health Facilities in Florida
- Strategic Planning Guide for Regional Coalitions (see Part 2 for county-level data, page 36)
PARTNER Evaluation

- PARTNER Survey Tool administered in 3 pilot coalitions in June 2012
  - Program to Analyze, Record and Track Networks to Enhance Relationships (see www.partnertool.net)
  - Measure connectivity and relationships in community partnerships using mapping techniques
  - Assess perceived value, quality of relationships; collaborative outcomes
  - Survey customized for each coalition
PARTNER Evaluation

- All 3 coalitions
  - Have fairly high level of trust among partner programs
  - Feel they’ve been at least somewhat successful in achieving coalition goals

- Coalitions differ in number and quality of organizational connections

- Each coalition ranked its partners by level of influence, involvement, contributions

- See summary of results at Coalition Evaluation
HillsboroughHATS
Density, Centralization, and Trust

N = 19 organizations/programs/departments
PanhandleHATS
Level of Involvement

Group Key
- Pediatric Medical Services
- Payer/Funder
- Mental/Behavioral Health
- Disability Services
- Clinic/Hospital
- Advocacy/Family Support
- Adult Medical Services
- Education
- Public Health

N=18 organizations
PARTNER Evaluation

- Use as benchmark for monitoring; track changes over time
- Use results to plan quality improvement activities
- Strengthen, increase linkages in community
- Coalitions can learn from each other, share experiences with new coalitions
  - Orlando, South Florida in discussions
State Plan Implementation:
2009-2012
Implement**ation**: 2009-2012

- Web Site and Social Media
- Health Services Directory for Young Adults
- Transition Toolkit
- Educational Materials
- Training Programs
- Publications
- Legislative Advocacy
Web Site and Social Media

Florida’s clearinghouse for health care transition information at www.FloridaHATS.org
Health Services Directory for Young Adults

Use the form below to search for health care programs and providers in your area that serve young adults, including those with disabilities or chronic health conditions.

Providers: For instructions on adding a service to our service directory or updating an existing entry, please visit our Submission Instructions page.

Disclaimer: A listing in this directory does not imply an endorsement from FloridaHATS, Florida Developmental Disabilities Council, Florida Department of Health, or Children’s Medical Services. 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:
- Project 10’s Florida District Resource Directory
- Florida Community Health Centers
- Healthy Athletes Resource Directory
- Find-a-Ride Florida Resource Directory
- CMS Provider Search
- 2-1-1 Helplines in Florida
- WaiverProvider.Com
- Where To Find Help in Florida
- Adult Primary Care Providers in Hillsborough County

Search By: Categories AND/OR Keyword(s)

City, State, County: -- Any City --
County: -- Any County --
Health Category: -- Any Health Category --
Search by Keyword(s): 

Submit Query Reset
Welcome

This Transition Toolkit was designed to provide a step-by-step approach to accessing resources that will help you with transition from pediatric care to adult care. The toolkit is designed for pediatric providers, other health care personnel (e.g., social workers, nurse care coordinators) and patients & families. The resources provide guidance or information to support youth and families during transition to adulthood and to adult health care. You will be asked a series of questions that will help determine which resources be most useful to you (depending on your role) to support the transition process.

Let's Get Started!

If you are a returning user, please use the login form at the right to complete and/or review your Transition Toolkit. If you are a first time user, please register to create a new account.
Educational Materials

Transition 2 Go
in Florida

School to Work Transition Vocational Rehabilitation

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

Including Those with Chronic Health Conditions or Disabilities

September 2011

10 Steps to Successful Health Care Transition

Success is the cornerstone of the new model of care for young adults with special health care needs. The care team focuses on the transition process to ensure young adults are prepared for health care timelines, coverage options, health maintenance, and tracking of health care needs.

1. Start early! Begin preparing for the transition even when you are a child. Having a plan can help you and your parents navigate the health care system.

2. Focus on relationships! The relationships you develop with your care team and insurance providers are crucial. Build a strong relationship with your care team to ensure you receive the care you need.

3. Create a health care summary. A comprehensive health care summary is essential for successful transition. Include all medical records, diagnostic tests, and immunization records.

4. Create a care coordination plan. Work with your care team to develop a plan that includes regular appointments, preventive care, and ongoing support.

5. Maintain written, updated health records that will continue into adulthood. Keep all medical records in one place, including electronic and paper copies.

6. Know your options for health insurance and public assistance programs. Be proactive in learning about available options and how they can benefit you.

7. Find adult providers. Build a network of adult providers that you trust and who are familiar with your medical history.

8. Integrate health care transition activities into the student’s educational planning. Develop a plan that includes regular check-ins with your care team and ongoing support.


Visit www.floridahats.org to view large print
Pare ayak, lalat na sitin. Kasi bata, handa ka na! (As a young person, you are ready.)

Shriners Hospitals for Children®
www.shrinershospitals.org
Training Programs

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
Legislative Advocacy

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 age 18-26 have special health care needs. Each year, almost 50,000 young Floridians with childhood onset conditions become adults. Advances in medical care have allowed this population to survive, but our current health care system does not adequately support them in adulthood.

50,000
Youth 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.
Looking Forward

- Promote Transition Toolkit
- Strengthen/expand regional coalitions
- Identify adult providers
  - Expand Health Services Directory for Young Adults
- Funding
  - Operational support
  - Study transition readiness among CMS Title V clients
  - Explore extending CMS care coordination to age 26
Contacts

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