FloridaHATS
Regional Coalitions

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FloridaHATS Project Director
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Background
Health care transition (HCT)
The purposeful, planned movement of adolescents and young adults, with and without SHCN, from child-centered to adult-oriented health care systems.

Preparation
Increased responsibility for health care self-management; understanding and planning for changes in health needs, insurance, and providers in adulthood; should occur across ages 12-21+

Transfer of care
Discrete event, physical transfer from a pediatric to an adult provider; should occur between ages 18-21+

Successful transition
Patients are engaged in and receive ongoing patient-centered adult care.
What can happen?

Without adequate support in moving from pediatric to adult care, youth may:

- Experience gaps/loss in insurance coverage
- 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; Digueperouxet 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.”
National survey of children with special health care needs

- Parent Survey
  - Every 4 years
  - State and National level reporting

- 4 questions about anticipatory guidance:
  - Changing health needs in adulthood
  - Transition to adult health provider
  - Insurance needs in adulthood
  - Youth encouraged to take increased responsibility for care
Data from 2009-2010 NS-CSHCN

- National average: 40% met HCT criteria
- States range: 32% - 53% met criteria
- Florida (ranked #39): 37% met criteria

Starting in 2016, new annual survey that includes HCT measures

- Combines National Survey of Children’s Health and NS-CSHCN
- First report due in 2017

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
Population model of HCT

Chronic Condition Care Coordination

Enhanced Planning

Transition Plan Assessment Information & Referral

Pediatric Care System

Adult Care System
National Center for Health Care Transition Improvement

www.gottransition.org
Six core elements of HCT

1. Develop transition policy
2. Establish tracking and monitoring
3. Assess transition readiness
4. Transition planning
5. Transfer of care
6. Transfer completion
Florida
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. Chiara, M.D., FAAP, Chair
Health Care Transition Services Task Force
January 1, 2009

2009 legislative report
Florida Title V 5-year plan for transition

Objectives

1. Increase the percentage of CMS Care Coordinators who receive transition-specific education and training annually.
2. Increase the percentage of providers and educators who receive information on how to access transition-specific education and training annually.
3. Increase the percentage of patients and families who receive transition-specific education and training annually.
4. Youth, families, and providers will have access to community-based resources necessary to facilitate and achieve successful health care transition.
5. Transition is recognized as a priority for the Department’s Title V Program.

Strategies

1. CMS Care Coordinators will receive transition education and training.
   2a. Providers are equipped with resources and education related to transition services and incorporating transition education as part of the annual well-child checkup.
   2b. Educators are provided with resources and education related to health care transition and incorporate health care self-management skills in Transition IEPs.
3. Youth with and without special health care needs and their families will receive transition-specific, age-appropriate education related to the following aspects of their lives: Work, Health care, Self-determination and self-management ability (power of attorney/guardianship), Secondary and post-secondary education
4. Transition support will be provided for youth, families, and providers.
5. CMS implements a transition program within the CMS organizational structure that includes specific programmatic outcomes related to quality improvement, measurable performance expectations, maintaining a transition registry, and ensuring provider adequacy.

ESMs

ESM 12.1 - Number of providers who have practices that have a HCT policy or youth with readiness assessment (with physicals) and plans of care.
FloridaHATS

Florida’s clearinghouse for HCT information
www.FloridaHATS.org
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
- FQHCs
- CHD
- CIL
- Mental Health
- Social Services
- School District

Family
- Y/YA
- Parents
- Caregivers
Regional coalitions

• Use a collaborative community planning model to develop local systems of transitional care
  ○ Goal to establish a coalition in each of 8 CMS regions

• Oversight and technical assistance from FloridaHATS

• 3 pilot sites in 2010 – mix of urban and rural
  ○ Tampa-Hillsborough County: HillsboroughHATS
  ○ Jacksonville-Duval County: Northeast FloridaHATS
  ○ Pensacola/Panama City Area: PanhandleHATS

• 4th regional coalition added in 2014
  ○ Miami/Ft. Lauderdale: South FloridaHATS
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 10-20 committed members.

<table>
<thead>
<tr>
<th>Organizations</th>
<th>Pediatric</th>
<th>Adult-Based</th>
<th>Notes</th>
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</thead>
<tbody>
<tr>
<td>Primary Care (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>Federally Qualified Health Centers</td>
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<td>Community Health Centers</td>
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<td>Free/Reduced Cost Clinics (We Care, Migrant/Indigent Care)</td>
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<td>Center for Independent Living</td>
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<td>Local Contact Person (Education)</td>
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<td>Funders and Policy Makers</td>
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<tr>
<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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<tr>
<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: Youth-Based</td>
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<td>Advocacy</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>Housing</td>
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<td>Employment</td>
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<td>Legal</td>
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<tr>
<td>Family Support Centers</td>
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<tr>
<td>Information &amp; Referral Programs (2-1-1)</td>
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</table>
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
*This plan was first developed in 2010 and was most recently updated October 2016. Items in red type were identified by coalition members as 2016-17 priority tasks.

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 patient’s life span. With the use of education and training, adequate funding and advanced technology, it is our goal to enhance the patient’s and family’s 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 healthcare 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 updated directly by Children’s Medical Services (CMS) staff, or submitted online by providers and other stakeholders. The directory was updated in the Spring of 2014, 56 new listings from USF CARD and 10 TGH Family Care Centers were added. The description of service section was expanded and fields added including languages spoken, whether the practice takes Medicaid, age range and populations served.</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>Services and Cross-System Relationship Building workgroup</td>
<td>Individuals to compile Information; Self Reliance Center for Independent Living</td>
<td>Identified multiple local and statewide resources: 2-1-1, Project 10 Directory, Special Olympics Directory, APD, VR, etc. Information on accessing support services is provided on the website. Individuals from these support agencies are regularly invited</td>
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</tbody>
</table>
Coalition implementation activities

- CMS/Escambia County Community Health Center (FQHC): Transition Referral and Navigation Model
- Expanded online service directory for Hillsborough County
- Interactive HCT Toolkit for case managers, medical providers, teachers, and families/youth
- “Ask Them 3” Cards
- Jax-YC
- Foster care, dental and behavioral health collaborations
- South Florida needs assessment for AYA with IDD
- Community events, school transition fairs
- Provider and educator training/outreach activities (Grand Rounds, resource packets, training events, school nurse education)
Coalition coordinator

- Provide leadership and support in implementing and updating coalition action plan
- Facilitate regularly scheduled coalition meetings
- Document activities performed along with progress towards strategic goals
- Recruit new members
- Knowledge of local issues, resources, systems of care, agencies, and providers that serve AYA with SHCN
- Requires approximately 15-25 hours per quarter; hours can vary from week to week, based on coalition needs
Challenges

• Finding a convenient time and location for meetings
• Limited availability of physicians for participation
• Engagement and continuity of membership (budget cuts, many are taking on more responsibility, staff turnover)
• Diverse group of agencies with varying degrees of knowledge and involvement in HCT
• Identifying agency roles and activities that are relevant across varying priorities and interests
• Regions cover large geographic areas, especially Panhandle and South Florida
Lessons learned

- Use existing resources and community collaborations
- Direct contact from coalition coordinator increases meeting participation
- Consider rotating between live and online meetings
- New/updated resource directory listings are best sourced from local CMS offices and coalition partners
- Opportunities for coalition replication: CMS/FQHC partnerships, youth council, medical-legal partnerships
- Suggestion for face-to-face workshops or a statewide transition conference for coalition members and other stakeholders to discuss their experiences and share best practices
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
  - Had fairly high levels of trust among partner programs
  - Felt they had been at least somewhat successful in achieving coalition goals

- Coalitions differed 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](#)
PanhandleHATS
Level of involvement

N=18 organizations
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