

**Meeting Summary  
Hillsborough HATS Coalition Meeting  
Children's Board of Hillsborough County  
February 8, 2010  
4:00-7:00 p.m.**

**Members in Attendance:**

Vicki Adelson	Melanie Hall	Dondra Smith
Glenn Brown	Doug Holt	Diane Straub
Robert Buzzeo	Karalee Kulek-Luzey	Joane White
Jeanine Fuentes (alternate for Jamie Parker)	John Mayo	Laura Williams
Maria Gieron	Kris Millrose	Laurie Woodard
	Tom Papin	
	Bruce Schnapf	

**Others in Attendance:**

Janet Hess  
Carla Gayle  
Teresa Kelly  
Debra Shaw

**Roll Call:** 17 members present

**Review and Revise Vision:**

The vision developed at the previous meeting was reviewed. A revision to the vision was proposed and accepted as follows:

*The Hillsborough HATS Regional Coalition works toward improving the transition process for youth and young adults with chronic-complex healthcare needs in the 21<sup>st</sup> 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, and families, quality of life for many years to come.*

**Community Themes and Strengths:**

The results of the survey were reviewed and additional input was solicited for the following questions:

1. What two or three things do you think are most important to *Youth and Young Adults* (Y/YA) with disabilities and chronic medical conditions in regard to health care transition?

Additional Responses:

- Understanding the policies and procedures for transition.
- Communication about transition for one to two years in advance.
- Having a family practitioner who can follow them through their lifespan.
- Better communication from pediatric Medipass provider to adult Medipass Provider.

2. What two or three things do you think are most important to the *families* of Y/YA with disabilities and chronic medical conditions in regard to health transition?

Additional Responses:

- Emphasizing to youth that they will eventually be responsible for their own care.
- Having health navigators assist families in developing transition plans.

3. What two or three things do you think are most important to *providers* of care for Y/YA with disabilities and chronic medical conditions in regard to health care transitions?

Additional Responses:

- Better coordination between inpatient/outpatient beyond medical record information.
- Training physicians in the developmental approach.
- Having checklists that can be used in transitioning youth.
- Knowledge of patient's health and social background issues prior to treatment.
- Holding patients accountable for their care.

Themes from the first three questions of the survey were summarized and participants were provided with three votes each to prioritize the areas of focus for the coalition. Participants were asked to share their definitions of the themes and as a result some categories were combined and totals for each are listed below:

What "Accessibility of Care" meant to group members:

- Having the insurance to cover necessary treatment
- Ability to have transportation
- Infrastructure present on multiple levels
- Availability of providers that will accept specific payment
- Physical availability (i.e. time, location)
- Basic access to providers
- Physical access (barrier free designed facilities)
- Language accessibility
- Co-location of services/nearby services; community-based approach
- Clarification of how to use Medi-pass appropriately
- Health navigators who are available and primarily responsible for working with patients and their families on a case-by-case basis.

- Provider has a knowledgeable skill set in order to appropriately refer patients to specialty

What “Payment for Medical Care and Coverage” meant to group members:

- Complexity and effort of a reimbursement and level of care required
- Allowing for creative solutions in treatment, as every case is different
- Allowing co-management of care among different providers of one patient (i.e. seeing patients together)
- Helping providers with knowing how to code
- Reimbursement for social work, nutrition, and other wrap-around services necessary to the transition process
- Information provided to patient and family on choosing the proper plans
- Eligibility for other insurances
- Social workers being located in clinics
- Inequities across funding sources
- A system that helps to navigate different services

What “Continuity and Coordination of Care” meant to group members:

- No lapses in treatment due to transition
- Knowledge for parents on what will immediately transpire, and what is left to anticipate
- Person or entity who specifically helps with the transition process, who must INDEPENDENT
- Case coordination among providers (Major Quality issue)

What “Education/Empowerment” meant to group members:

- Health literacy for patients and families in the developmental approach
- Encourage patients to learn about their diseases
- Educate patients on the difference between adult health care and pediatric care

Due to cross over between categories based on participant’s definitions, theme priority rankings were combined as follows and total scores are indicated:

Accessibility of Care/ Payment for Medical Care and Insurance Coverage (18)

Continuity and Coordination of Care/ Information Sharing/

Communications/Relationship Building (15)

Education/Empowerment/Training (9)

Support Services and continued eligibility for services (6)

Participants reviewed the responses to question 4 and added the following observations.

4. Describe what elements of the current health care transition work well for Youth and Young Adults (Y/YA).

### Additional responses:

- The availability of the general health care transition guide and resource guide from Janet Hess is helpful.
- If a patient has good documentation summaries of their medical history, things are smoother.
- When there is trust between patients and physicians, transition is easier to navigate.
- “Connected by 25”: A program that seeks to wrap children in a bunch of support services outside of their medical services that ensures that they will be connected to the world by the age of 25. Right now this is being used in foster care. \*Possible asset for HATS
- CF Model: Checklist followed in order to access multidisciplinary sites. It is a networking process where providers know where patients are going. (\*current project involves USF & TGH, and is being funded by TGH).
- Having trained confidants that patients know and able to speak with.
- Becoming familiar with other providers to refer/consult with.

### Gap Analysis

Identified gaps were reviewed. An additional gap identified was that some Y/YA have multiple system involvements (such as Juvenile Justice, Child Welfare, etc.) and no mechanism for coordination exists to serve this population.

### Resources

Identified resources were reviewed and additional resources were identified as follows:

- Recognition of Hillsborough County’s wealth of resources; has a very rich history of collaboration
- Shriners’ Children Hospital is very beneficial
- Health Department is a great resource for patients and their families
- Medical Home model (American Academy of Pediatrics)
- Home Health agencies can assist with some case management issues.
- Free clinics in Hillsborough County can provide some services for Y/YA.
- MedNet program can assist with enrollment in compassionate use programs for qualified individuals.
- 

Groups currently collaborating/have potential to participate in the transition process:

- Hillsborough County Health Plan has a relationship with CMS to assist in transition. Health plan expanding efforts to make people self-sufficient with offering job training and placement assistance and linkages to other social services as wrap around to help people move to other means of obtaining health care.

- Florida Alliance for Assisted Technology aids in providing loans and private insurance.
- USF (active program for individuals living with disabilities)
- School Support Teams

Additional discussion:

- Physician office and clinic staff (receptionist, greeters) can really make or break the relationship between patient and providers
- Discussing the role of other important providers, not just physicians (i.e. Physician Assistants, Nurse Practitioners, etc.)
- Local government that has worked with transition program.
- Awareness of transition issues is improving.

### **Wrap-up and Next Steps:**

Topic for the next meeting includes Forces of Change assessment. Teresa reviewed the following:

What are Forces of Change?

Forces are broad, all-encompassing category that includes trends, events and factors.

Trends are patterns overtime, such as migration in and out of a community or a growing disillusionment with government.

Factors are discrete elements, such as migration in and out of a community's large ethnic population, being an urban setting or a jurisdiction's proximity to a major waterway.

Events are one-time occurrences, such as a hospital closure, a natural disaster or new legislation.

All types of forces, including social, economic, political, technological, environmental, scientific, legal and ethical should be considered.

Participants will be provided with a brainstorming worksheet to prepare for the next meeting.