

Final Report

Health Care Transition

October 2009 - June 2010



David Libby, Chairman
Elizabeth Rugg, Executive Director
Kathy LaRoche, Business Development and Planning Director
Teresa Kelly, Special Projects Coordinator
Carla Gayle, MPH Intern

WHO WE ARE

The health councils were created in 1983 by Florida Statute to identify, address and resolve health care issues of local concern. Each health council is a private, non-profit organization governed by a Board of Directors. The Board members are appointed by County Commissioners to represent the concerns of health care consumers, providers and purchasers.

The Health Council of West Central Florida, Inc. (HCWCF) serves Hardee, Highlands, Hillsborough, Manatee and Polk counties. The Council has extensive experience working with for-profit and non-profit agencies, public health organizations, consumers and professionals. Collaboration and cooperation are critical to the success of our mission.

We have three strategic goals: (1) support the accessibility of health care and social support systems through *comprehensive health planning*; (2) obtain and provide *education* about essential community health challenges and solutions; and (3) participate as collaborative partners to address current and emerging health issues to develop and sustain efficient and cost effective *service delivery* systems.

HEALTH COUNCIL OF WEST CENTRAL FLORIDA, INC. BOARD OF DIRECTORS

Dr. Ronald Berezniak, Manatee
Joel Chudnow, Hillsborough
Ray Dielman, Manatee (Vice Chair)
Melonie Hall, Hillsborough
David Libby, Polk (Chair)
Carole Mackey, Hillsborough
Russell Patterson, Hillsborough

TO LEARN MORE ABOUT THE HEALTH COUNCIL

Visit our website - www.healthcouncils.org

Or Contact Us:

Health Council of West Central Florida, Inc.
9600 Koger Blvd., Suite 221
St. Petersburg, FL 33702
727-217-7070
727-570-3033 (Fax)

Overview

The Health Council of West Central Florida, Inc. (HCWCF) provided technical assistance to the Florida Health Care Transition Initiative to organize and launch local/regional health care transition coalitions. Specifically, the contract had three components: data collection; strategic planning; and mentoring/technical assistance to PanhandleHATS staff. The Final Report summarizes HCWCF's activities on behalf of the Florida Health Care Transition Initiative and provides copies of agendas, meeting summaries, and planning tools. The Coalition's adopted Action Plan is available as a separate document.

A. Data Compilation

HCWCF compiled secondary data by county, DOH/CMS geographic areas (6) and state, as available and developed a document displaying the data in a useable format. The Healthcare Transitions Data Report was shared with the two other pilot locations (Jacksonville and Panhandle) for use in their strategic planning efforts. The Report will be available to new coalitions as they are launched in other areas of Florida. Data elements included:

- General Population Characteristics (age, sex, race, ethnicity, number of households, household size, linguistics)
- Demographics of Disabled Population (type by gender and sex, employment, income, education, clinical diagnosis, out of home, CMS clients, SSI, mental health services, mental health disorders, students by support level)
- Community-based Medical Services (resource listing by county)
- Local Planning Councils (contact information for additional studies)

B. Strategic Planning

1. Steering Committee

A Steering Committee was convened to provide guidance in the development of the pilot coalition for Hillsborough County. The Steering Committee consisted of representatives from Children's Medical Services, University of South Florida, Shriners Hospitals for Children-Tampa and private healthcare providers. During its three meetings, the Committee developed a list of potential coalition members based on categories; selected meeting dates/times/locations; drafted the invitation letter; approved the agenda for the first meeting and recommended orientation materials for the coalition members. Steering Committee agendas and meetings summaries are found in Attachment A. Copies of the invitation letter, coalition fact sheet, meeting calendar and member registration form are provided in Attachment B.

2. Coalition Development and Strategic Planning

Five meetings were held between January and May 2010. See Attachment C for agendas, meeting summaries and the evaluation results. Planning tools used by the Coalition are found in Attachment D. A list of the 23 representatives who served on the HillsboroughHATS Coalition is found in Attachment E. The following activities were conducted at the meetings:

January Meeting

- Project Introduction and Overview
- Objectives and Timeline
- Review of Data Report
- Visioning Exercise

February Meeting

- Community Themes & Strengths
- Gap Analysis

March Meeting

- Forces of Change Assessment
- Strategic Issue Identification

April Meeting

- Strategic Issue Prioritization (PEACH)
- Goals and Objectives

May Meeting

- Action Steps
- Strategic Plan Approval
- Next Steps for Coalition
- Member Evaluation

C. Mentoring/Technical Assistance to PanhandleHATS staff

HCWCF provided mentoring/technical assistance to the PanhandleHATS coalition's facilitator (Big Bend/Northwest Florida Health Council staff) from mid-February through May 2010. Assistance was provided over the telephone regarding meeting plans, tools, methodology, and materials. The HCWCF assumed no responsibility for the outcomes of the PanhandleHATS coalition.

Attachment A

Steering Committee Agendas/Meeting Summaries

October 20, 2009
November 12, 2009
November 24, 2009



HEALTH CARE TRANSITION STEERING COMMITTEE
October 20, 2009
10:00 a.m. to 11:30 a.m.
Shriners Hospital Board Room

Agenda

- | | |
|--|----------------|
| I. Introductions and Coalition Timeline | Kathey LaRoche |
| II. Identify Potential Members (target: 12-25) | Janet Hess |
| III. January Coalition Meeting
- Dates/times
- Possible locations | Kathey LaRoche |
| IV. Invitation Letter | Kathey LaRoche |
| V. Select Date for <u>Next</u> Steering Committee Meeting
Possible dates/times:
- Wednesday, November 4 @ 1 p.m.
- Friday, November 6 @ 10:30 a.m.
- Monday, November 9 @ 10:30 a.m. | Kathey LaRoche |

COALITION TIMELINE

1. Maximum three meetings with Hillsborough County Steering Committee to identify invitees, select the first meeting date and location, and finalize invitation letter and the first meeting agenda. (October - November 2009)
2. Secure commitments from invitees to join Hillsborough County Coalition. (November - December 2009)
3. Facilitate five coalition meetings (3-4 hours each) to carryout strategic planning activities. (January - June 2010)
4. Provide action plan and final report to J. Hess. (June 10, 2010)



HEALTH CARE TRANSITION STEERING COMMITTEE October 20, 2009 Meeting Summary

Attendance: Joanne Angel, Janet Hess, Martha Kronk, Kathey LaRoche, Kris Millrose, Julie Perez, Elizabeth Rugg, Diane Straub, Laurie Woodard

Kathey LaRoche reviewed the coalition timeline:

- Maximum three meetings with Hillsborough County Steering Committee to identify invitees, select the first meeting date and location, and finalize invitation letter and the first meeting agenda. (October - November 2009)
- Secure commitments from invitees to join Hillsborough County Coalition. (November - December 2009)
- Facilitate five coalition meetings (3-4 hours each) to carryout strategic planning activities. (January - June 2010)
- Provide action plan and final report to J. Hess. (June 10, 2010)

Kathey also reviewed the agenda for today's meeting and explained that unfinished items would be rolled forward to the next meeting agenda.

Janet Hess reviewed with the group the Member Worksheet and collected recommendations for the categories on page one. Various members volunteered to provide Janet with lists including contact information so she can compile them into a roster of possible members. It is anticipated that the final roster will need to be culled to bring the group into a reasonable size. Kathey mentioned that the Committee might want to allow each member to appoint an official alternate to assure participation of all members (or their alternate) at all five Coalition meetings.

The Committee tabled action of the January Coalition meeting date/time and location until the next meeting. There was general agreement to alternate meeting locations between northern Hillsborough (USF area) and the Tampa area (Children's Board or Jan Platt Library).

The Committee tabled action on the invitation letter. There was preliminary discussion of the need to make personal appeals to individuals in addition to the letter; the use of photos on the letter; the use of the Fact Sheet as an attachment to the letter.

The Committee agreed to meet again on November 4th at 1 p.m. at the same location.



HEALTH CARE TRANSITION STEERING COMMITTEE
November 12, 2009
10:30 a.m.
Shriners Hospital Board Room

Agenda

- | | |
|--|----------------|
| I. Coalition Meetings
- Dates/Times
- Locations | Kathey LaRoche |
| II. Invitation Letter | Janet Hess |
| III. Potential Members | Janet Hess |
| IV. <u>Next</u> Steering Committee Meeting
November 24 at 10:30 a.m. @ Children's Board | Kathey LaRoche |

COALITION TIMELINE

1. Maximum three meetings with Hillsborough County Steering Committee to identify invitees, select the first meeting date and location, and finalize invitation letter and the first meeting agenda. (October - November 2009)
2. Secure commitments from invitees to join Hillsborough County Coalition. (November - December 2009)
3. Facilitate five coalition meetings (3-4 hours each) to carryout strategic planning activities. (January - June 2010)
4. Provide action plan and final report to J. Hess. (June 10, 2010)



HEALTH CARE TRANSITION STEERING COMMITTEE November 24, 2009 Meeting Summary

Attendance: Joanne Angel, Janet Hess, Martha Kronk, Kathey LaRoche, Julie Perez,

Kathey LaRoche reviewed the calendar for the five coalition meetings, which will be held the second Monday of each month from 4:00 p.m. to 7:00 p.m. Meeting locations will alternate between Shriners Hospital at USF and Children's Board of Hillsborough. The agenda for the first meeting will include a welcome by David Wood and a ten minute overview of the statewide project by Janet Hess followed by the other items listed on the calendar.

Janet reviewed the final version of the invitation packet, which includes an individualized letter; HCT fact sheet; calendar of dates/locations/topics (with description of MAPP); and a response form (with contact information and alternate delegation). The letters will be sent by November 30 with a response request by December 8.

Janet Hess reviewed the recommendation roster which totaled 53. The Committee agreed to place some individuals on a back-up list to generate a list of no more than 40 to receive invitation letters. The remaining names would be used in the second round to replace invitees who decline to participate and/or for future Coalition activities including the survey. The MAPP and PEACH processes require that we keep the group size to 25 (ideal) and 30 (maximum). Janet will send the list to Dr. Curran for his approval.

The Committee will meet on November 24th at 10:30 a.m. at the Children's Board to finalize the letter and invitee list.



HEALTH CARE TRANSITION STEERING COMMITTEE
November 24, 2009
10:30 a.m.
Shriners Hospital Board Room

Agenda

- | | |
|---|---------------|
| I. FINAL Coalition Meeting Schedule
- Dates/locations/agenda | Kathy LaRoche |
| II. FINAL Invitation Letter w/Attachments
- Mail out deadline: November 30 | Janet Hess |
| III. FINAL Coalition Invitee List
- Follow-up phone call assignments | Janet Hess |
| IV. Other Issues | Members |

COALITION TIMELINE

1. Maximum three meetings with Hillsborough County Steering Committee to identify invitees, select the first meeting date and location, and finalize invitation letter and the first meeting agenda. (October - November 2009)
2. Secure commitments from invitees to join Hillsborough County Coalition. (November - December 2009)
3. Facilitate five coalition meetings (3-4 hours each) to carryout strategic planning activities. (January - June 2010)
4. Provide action plan and final report to J. Hess. (June 10, 2010)



HEALTH CARE TRANSITION STEERING COMMITTEE November 24, 2009 Meeting Summary

Attendance: Joanne Angel, Janet Hess, Martha Kronk, Kathey LaRoche, Julie Perez

Kathey LaRoche reviewed the calendar for the five coalition meetings, which will be held the second Monday of each month from 4:00 p.m. to 7:00 p.m. Meeting locations will alternate between Shriners Hospital at USF and Children's Board of Hillsborough. The agenda for the first meeting will include a welcome by David Wood; a ten minute overview of the statewide project by Janet Hess; followed by the other items listed on the calendar.

Janet Hess reviewed the final version of the invitation packet, which includes an individualized letter; HAT fact sheet; calendar of dates/locations/topics (with description of MAPP); and a response form (with contact information and alternate delegate). The letters will be sent by November 30 with a response requested by December 8.

Janet Hess reviewed the recommended roster which totaled 53. The Committee agreed to place some individuals on a back-up list to generate a list of no more than 40 to receive invitation letters. The remaining names would be used in the second round to replace invitees who decline to participate and/or for future Coalition activities including the survey. The MAPP and PEACH processes require that we keep the group size to 25 (ideal) and 30 (maximum). Janet will send the list to Dr. Curran for his approval. Committee members will notify Janet which invitees they will personally contact.

In other business, the Steering Committee will be contacted by Janet for feedback on the draft survey questions. No additional meetings are planned at this time. Members were thanked for their valuable input in planning the Coalition.

Attachment B

Invitation Letter
Coalition Fact Sheet
Meeting Calendar
Member Registration Form



Charlie Crist
Governor

Ana M. Viamonte Ros, M.D., M.P.H.
State Surgeon General

November 30, 2009

Dear _____,

Many youth and young adults are falling through the cracks of our fragmented health care system and it is time we organize our communities to better meet the needs of these young people.

You have been selected as a critical community partner to participate in a coalition co-sponsored by the Florida Department of Health, Children's Medical Services, and Florida Developmental Disabilities Council, Inc. The purpose of the HillsboroughHATS (Health and Transition Services) Coalition is to facilitate successful transition from pediatric to adult-based health care for all youth and young adults in Hillsborough County, including those with special health care needs or disabilities.

As its first activity, HillsboroughHATS members will participate in community-wide strategic planning. You or your alternate will attend a series of five meetings to learn about the issues facing young people in Hillsborough County as they move to adult health care, and to work as a group to define priorities to improve our local system of care (see attached meeting calendar). The kick-off for the Coalition is:

Monday, January 11, 2009
4:00 – 7:00 P.M.
Shriners Hospital at USF
12502 USF Pine Drive
Tampa, FL 33612

Feel free to arrive early to sign in, enjoy some refreshments, and network with other partners. You will find attached additional information about HillsboroughHATS.

Please RSVP by December 8 to confirm your attendance using the attached response form. Should you have any questions regarding the Coalition, please contact Kathey LaRoche at 727-217-7070, ext. 17, or klaroche@healthcouncils.org.

Health care transition is a critical component of successful entry to adulthood for young people with special health care needs. Please let us know that you will join us as a HillsboroughHATS Coalition partner.

Sincerely,

A handwritten signature in blue ink, appearing to read "Joseph J. Chiaro".

Joseph J. Chiaro, M.D.
Deputy Secretary
Children's Medical Services

A handwritten signature in blue ink, appearing to read "John Curran".

John Curran, M.D.
Tampa Bay Region Medical Director
Children's Medical Services

HillsboroughHATS (Health and Transition Services) Coalition Fact Sheet

What: A local coalition charged with designing and implementing a service delivery model that fits the unique needs and resources of the community and includes pediatric and adult providers.

Who: HillsboroughHATS members represent youth and young adults with special health care needs or disabilities, families, pediatric and adult health care providers, and other stakeholders in Hillsborough County.

Why: Transition from the pediatric to the adult health care system for youth with special health care needs or disabilities is full of issues and barriers. Tailoring programs to individual needs, concerns and issues is the key.

In July 2008 Florida legislation established a statewide Task Force to assess the need for health care transition services, develop strategies to ensure successful transition from pediatric to adult health care systems, and identify existing and potential funding sources. The Task Force Report issued December 2008 included among its recommendations the development of local transition coalitions. Hillsborough County was selected as a pilot site. Additional information about the statewide Task Force can be found at www.healthcaretransition.org.

When: During Fall 2009 community members will be invited to participate in the HillsboroughHATS Coalition. The first meeting will take place in January 2010 with additional monthly meetings planned through May.

How: Between January and May 2010 the Coalition will be guided through a strategic planning process that includes orientation to the project; review of local data concerning youth and young adults; assessments and identifying strategic issues; priority setting and adoption of an action plan.

Contact: Kathey LaRoche, Business Development and Planning Director
Health Council of West Central Florida 727-217-7070, ext. 17 or
klaroche@healthcouncils.org



HillsboroughHATS Coalition Meeting Calendar for January - May 2010

#	Date & Time	Location of Meeting	Purpose of Meeting
1	Monday, January 11 4:00 - 7:00 P.M.	Shriners Hospital @ USF 12502 USF Pine Drive Tampa, FL 33612 Ph 813-972-2250	<ul style="list-style-type: none"> • Project Introduction & Overview • Objectives & Timeline • Data Review • Visioning Exercise
2	Monday, February 8 4:00 - 7:00 P.M.	Children's Board 1002 East Palm Avenue Tampa, FL 33605 Ph 813-229-2884	<ul style="list-style-type: none"> • Community Themes & Strengths • Health Care Transition System Assessment & Gap Analysis
3	Monday, March 8 4:00 - 7:00 p.m.	Shriners Hospital @ USF 12502 USF Pine Drive Tampa, FL 33612 Ph 813-972-2250	<ul style="list-style-type: none"> • Survey Results • Forces of Change Assessment • Strategic Issue Identification
4	Monday, April 12 4:00 - 7:00 P.M.	Children's Board 1002 East Palm Avenue Tampa, FL 33605 Ph 813-229-2884	<ul style="list-style-type: none"> • Strategic Issue Prioritization (PEACH) • Goal & Strategy Development
5	Monday, May 10 4:00 - 7:00 P.M.	Shriners Hospital @ USF 12502 USF Pine Drive Tampa, FL 33612 Ph 813-972-2250	<ul style="list-style-type: none"> • Action Steps • Strategic Plan Approval • Next Steps for Coalition

Coalition meetings will utilize a strategic planning tool called Mobilizing for Action through Planning and Partnerships (MAPP). Using MAPP, communities seek to achieve optimal health by identifying and using their resources wisely, taking into account their unique circumstances and needs, and forming effective partnerships for strategic action. The overall goal of the model is to improve the health care transition service delivery system and increase collaboration among providers in Hillsborough County. The graphic below displays the MAPP process.



**HillsboroughHATS Coalition
Member Registration**

Please return this form indicating your willingness to serve on the HillsboroughHATS Coalition by December 8th to the fax number or address listed below.

___ YES, I am willing to accept the nomination to serve on HillsboroughHATS and participate in the five meetings listed on the Coalition calendar.

___ NO, I am unable to serve on the HillsboroughHATS Coalition.

MY CONTACT INFORMATION

Name: _____

Address: _____

Phone #: _____

Cell #: _____

E-mail: _____

Preferred Method of Contact: ___ Phone ___ Cell ___ E-mail

MY ALTERNATE

Each voting member is encouraged to designate an official alternate who can vote on their behalf at meetings. Please indicate your designated alternate below.

Name: _____

E-mail: _____

Phone #: _____

RETURN FORM VIA FAX # 727-570-3033

or MAIL TO: HCWCF

9600 KOGER BLVD., SUITE 221

ST. PETERSBURG, FL 33702

Attachment C

Coalition Agendas/Meeting Summaries/Evaluation

January 11, 2010

February 8, 2010

March 8, 2010

April 12, 2010

May 10, 2010

HillsboroughHATS Coalition
January 11, 2010
4:00 - 7:00 p.m.
Shriners Hospital Auditorium

Agenda

4:00-4:15	Roll Call	Teresa Kelly Coalition Facilitator
4:15-4:30	Welcome	Dr. David Wood Task Force Member
4:30-4:45	Florida Health Care Transition Project	Janet Hess Project Director
4:45-5:00	Coalition's Objectives and Timeline	Teresa Kelly Coalition Facilitator
5:00-5:30	Review of HAT Summary Data Report	Teresa Kelly Coalition Facilitator
5:30-6:45	Visioning Exercise	Teresa Kelly Coalition Facilitator
6:45-7:00	Wrap-up and Next Steps	Teresa Kelly Coalition Facilitator
7:00	Adjourn	

Please note: Next Meeting Date: February 8 at Children's Board

Meeting Summary
Hillsborough HATS Coalition Meeting
January 11, 2010
4:00-7:00 p.m.
Shriners Hospital Auditorium

Members in Attendance:

Joanne Angel
Glenn Brown
Robert Buzzeo
Melanie Hall
Doug Holt
Martha Kronk
Karalee Kulek-Luzey
John Mayo
Tom Papin
Jamie Parker
David J. Plasencia
Cheryl Reed
Lynn Ringenberg
Bruce Schnapf
Dondra Smith
Sharon Dabrow (Alternate to Diane Straub)
Federico Valadez
Joane White
Laura Williams
Laurie Woodard

Others in Attendance:

John Curran, MD
Janet Hess
Carla Gayle
Teresa Kelly
Maria Tamayo
David Wood, MD

Roll Call: 21 members present

Welcome and Project Overview:

Dr. John Curran welcomed members of the coalition and expressed his gratitude for their commitment to this effort.

Dr. David Wood and Janet Hess presented on the need for the creation of an efficient transition system and the activities of the Statewide Task Force on Health Transitions (Slides provided to members at the meeting).

Coalition's Objectives and Timeline:

Teresa Kelly reviewed the meeting calendar and explained the process for the next four meetings. Members will have homework assignments sent to them and were asked to come prepared for each meeting. The final outcome of the project will be the development of an action plan.

Review of Florida HATS Data Report:

Teresa Kelly presented Hillsborough County data related to Youth and Young Adults with disabilities and health manpower resources. (Slides provided to members at the meeting)

Visioning Exercise:

Teresa Kelly led the coalition in a visioning exercise. This activity was used to explore and describe the ideal transition system, and describe how the transition system could improve the quality of life for patients and their families. The group proceeded with a half-hour discussion on various ideas and improvements to the transition process (notes attached). After the discussion, the group split into seven groups, and created their own individual vision statement for the HillsboroughHATS. At the conclusion of each group presentation, the coalition worked together to come up with one vision statement.

Vision Statement:

The HillsboroughHATS is a regional coalition that supports patient and family-centered access to a continuum of care for youth and young adults with chronic-complex healthcare needs throughout their lifespan.

Utilizing education and training, adequate funding, use of technology and medical information portability, we enhance the quality of life for patients and families.

The coalition will review the vision at the next meeting and make final adjustments.

Wrap-up and Next Steps:

Teresa Kelly informed group that homework assignments and meeting notes would be forwarded to them later in the week. Teresa will review the notes and highlight the values expressed during the discussion which will be included with the meeting summary.

Since there is no funding for food for future meetings, members agreed that they could contribute \$5.00 towards food if they wished to have something to eat. Members will notify Teresa if they wish to participate, so that Janet can provide the

appropriate amount of food. Members will be asked to bring \$5.00 in cash to the meeting.

Vision Notes

Awareness:

- Awareness within the community at large
- Awareness of the role of culture
- More general knowledge of patient backgrounds
- Awareness of/easy accessibility to necessary resources (i.e. Care Coordination)
- Awareness of insurance options for both patients and families of Youth and Young Adults
- Care continuation of the whole human life span vs. specific stage
- Awareness of options/self-determination/self-management of condition
- Focus/Emphasis on the Language Barrier
- Emphasis on patient/provider literacy in the discharge procedure

Collaboration:

- Prior planning before 1st visit to adult doctor and appropriate collaboration after
- Identify an appropriate balance of goals between patient/family and provider
- Referral group of physicians willing to work with the more complex issues
- Improved communication between healthcare and education systems
- Incorporating school nurses into the transition
- Possible combination of provider/school education on complex conditions
- Working with schools to improve self management of conditions, and how to be a healthcare consumer (incorporation into curriculum)

Systematic Improvements:

- Continuous financial support
- Interdisciplinary care
- Electronic Medical Record System
- Comprehensive Discharge plans
- Improving accessibility to Medicaid resources
- Compensation for amount of time required for more complex issues
- Additional compensation for those working directly with complex needs
- Gap between how we involve/treat patients and families
- Quality measures
- Increased access to transportation
- Identifying centers/specialists who will see more complex issues
- More frequent use of the CMS Assessment tool
- Model Cystic Fibrosis
- Developing a step guide
- Developing a template for providers/patients to follow for successful transition
- Model CMS (establishing a core task list for providers to follow)
- More participation from Adult providers
- Developing a network with Continued Medical Education (CME)

- Clinical Guidelines/Standards of Care
- Center for adults which also accessible to the community
- Integrated systems for medically complex individuals
- Social support needs
- Mental health needs
- Continuity of care
- Improved communication among providers
- Importance of families continued involvement in adulthood care
- A “future” planning mentality vs. “crisis to crisis” mentality
- Healthcare transition timeline for families

Education/Training:

- Training for provider network
- More Medical School curriculum geared towards disabilities
- Improved training for complex disorders
- Emphasis on prevention education
- Teaching medical students about the future of pediatric care and the treatment of chronic patients
- Certification of providers
- Teaching patients to be experts in their own lives
- Teaching families how to plan for transition

Values for a Health Care Transition System

- Culturally and linguistically appropriate
- Patient and family centered
- Effective communications
- Collaborative with other social institutions and health care providers
- Interdisciplinary/Coordinated care
- Fair compensation to providers
- Accessible
- High quality care

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

Agenda

4:00-4:15	Roll Call	Teresa Kelly Coalition Facilitator
4:15-4:30	Review/Revise Vision	Teresa Kelly Coalition Facilitator
4:30-5:45	Community Themes and Strengths	Teresa Kelly
5:45-6:30	Gap Analysis	Teresa Kelly Coalition Facilitator
6:45-7:00	Wrap-up and Next Steps	Teresa Kelly Coalition Facilitator
7:00	Adjourn	

Please note: Next Meeting Date: March 8 at Shriners Hospital

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

Members in Attendance:

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

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 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, 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 form 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 be 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 Hospital for Children 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.

HillsboroughHATS Coalition
March 8, 2010
4:00 - 7:00 p.m.
Shriners Hospital Auditorium

Agenda

4:00-4:15	Roll Call	Teresa Kelly Coalition Facilitator
4:15-4:30	Review of Activities to Date	Teresa Kelly Coalition Facilitator
4:30-4:45	Forces of Change Assessment	Teresa Kelly Coalition Facilitator
5:45-6:45	Strategic Issue Identification	Teresa Kelly Coalition Facilitator
6:45-7:00	Wrap-up and Next Steps	Teresa Kelly Coalition Facilitator
7:00	Adjourn	

Next Meeting Date is April 12, 2010 at the Children's Board of Hillsborough County

**Meeting Summary
HillsboroughHATS Coalition Meeting
Shriners Hospital
March 8, 2010
4:00-7:00 p.m.**

Members in Attendance:

Vicki Adelson
Joanne Angel
Glenn Brown
Robert Buzzeo
Maria Gieron
Doug Holt
Martha Kronk
Debra Shaw (Alternate
for Karalee Kulek-
Luzey)
Maria Tamayo
(Alternate for John
Mayo)
Kris Millrose
Jamie Parker
David Plasencia
Cheryl Reed
Lynn Ringenberg
Dondra Smith
Diane Straub
Federico Valadez
Joane White
Laurie Woodard

Others in Attendance:

Carla Gayle
Teresa Kelly

Roll Call: 19 members
present

Review of Activities to Date:

Teresa Kelly provided an overview of the work done to date and explained how all the exercises would begin fitting together today. Community health and manpower data, community themes and strengths, gap analysis and what is working, and forces of change all feed into the identification of strategic issues.

Forces of Change

The definition of Forces of Change was reviewed. Members offered their observations noting that some items were both a threat and an opportunity. The following forces of change were identified.

Threats

1. Decreasing resources, bad economy, shrinking government
2. County resources unable to expand to needed areas/respond accordingly
3. National health care reform
4. Medipass/Medicaid share of cost programs may be losing funding
5. Lack of Spanish-speaking providers
6. Lack of translation services for other languages
7. Influx of refugees; need for refugee health, increased language/cultural barriers
8. Lack of support from the family units/Transient population
9. Lack of job/employment opportunities
10. Lack of physicians wanting to practice in Florida
11. State budget shortfalls with reductions targeting vulnerable populations
12. Fewer primary care providers
13. Increasing number of persons with complex medical needs and disabilities being born and surviving into adulthood due to improvements in technology, but no increase in funding and services to meet the need
14. Budget cuts in other supporting institutions such as education

Opportunities

1. Technology is impacting increasing lifespan and population and allowing for more productive lives
2. Electronic medical records
3. By having a diverse population it potentially provides us with the opportunity to have providers skilled in cultural competency and languages needed
4. Local focus on development of infrastructure that makes the city a more "workable" city (i.e. transportation, diverse economy, etc.)
5. Technology is offering more innovative solutions to medical problems/issues
6. There is an increase in the number of mid-level providers (i.e. ARNPs, PAs)
7. Increasing awareness among medical students and healthcare providers on individuals with special needs

8. Advanced technology in communication devices. This increase in technology allows for enhanced communication between providers and their patients (i.e. Telemedicine)
9. National health care reform
10. Medicaid reform may provide opportunity for Hillsborough County to be a pilot site for Medical Home model.
11. Medical School and service providers exist in our area - provides opportunity to build a system

Strategic Issue Identification

Teresa Kelly provided an overview of strategic issues and how they should be defined.

What are Strategic Issues?

- Important, forward-thinking, and are able to seize current opportunities
- Require either immediate or future action
- Require action on behalf of system partners
- Have no obvious best solution
- Should be stated in the form of a question without the use of jargon
- Issue and goals that come from
 - strengths to be built upon
 - weaknesses to be strengthened
 - opportunities to be taken
 - threats to be avoided
- Fundamental choices centered around tension and conflict to be resolved
- Something that can be addressed
- Focus on *issues*, and not answers at this time.

Participants were divided up into five groups to work on the identification of strategic issues and were asked to answer the following questions about each issue:

1. Identify the strategic issue. Phrase the issue as a question.
2. Does this strategic issue require immediate or future action? (Can include monitoring for future action).
3. What are the consequences of not addressing this issue?

Strategic Issues Identification

Funding		
Strategic Issue	Immediate or Future Action?	Consequences
1. How do we affect/impact funding changes for long term services for youth and young adults with special health care needs?	Immediate: Establish grass roots legislation Future Action: Use grass roots initiative to mandate funding	<ul style="list-style-type: none"> • Continued spiraling costs of health care. • Death from a lack of appropriate care.
2. How can providers, both general and specialized, ensure that they will effectively treat their patients regardless of the insurance provided?	Both	<ul style="list-style-type: none"> • Gaps in services • Increased morbidity and mortality • Lack of services
3. How do we prioritize allocation of resources?	Immediate	<ul style="list-style-type: none"> • Individuals falling through the cracks and not maximizing use of appropriate resources to achieve the highest level of functionality for people in need
4. How do we fund primary medical and ancillary services for transitioning youth and young adults with special health care needs? (i.e. reimbursement rates, infrastructure to provide care and care coordination)	Both	<ul style="list-style-type: none"> • Gaps in services • Increased morbidity and mortality • Lack of services
Education (General Public/Providers/YYA and their families)		
Strategic Issue	Immediate or Future Action?	Consequences
1. How do we strengthen public awareness on issues affecting the daily lives of people with disabilities (physical and mental)?	Immediate	<ul style="list-style-type: none"> • Continued lack of awareness of issues and loss of opportunity to achieve desired goals
2. How can we better network between pediatric and adult healthcare providers and support services to help patients and their families with transitioning?	Immediate	<ul style="list-style-type: none"> • Lack of enthusiasm, and willingness, from providers
3. How can the school system help educate transitioning Youth & Young Adults about health care in this era of economic difficulty?	Both	<ul style="list-style-type: none"> • Uneducated adult health care consumers • Missed opportunities to maximize care & health

Strategic Issue	Immediate or Future Action?	Consequences
4. How can pediatric providers ensure that their patients have an adequate understanding of the responsibility of their own care following their transition?	Immediate	<ul style="list-style-type: none"> Lack of appropriate care when not in the presence of family or provider Lack of understanding in the complexity of patients' condition
6. How can we improve the guardianship process including education/awareness, cost, efficiency and protection of individual rights?	Both	<ul style="list-style-type: none"> Delays, or lack in care & treatment Exploitation of resources and violation of individual rights
7. How do we address the discomfort of adult health care providers in treating adults with disabilities?	Both (education- training in medical schools)	<ul style="list-style-type: none"> Continued discomfort and lack of or willingness to provide care services
8. How can we ensure that medical schools appropriately train physicians in the developmental approach in regards to working with specialty populations? Specifically, must additional competencies or curriculum be implemented in order to ensure adequate coverage of specialty populations?	Both (education- training in medical schools)	<ul style="list-style-type: none"> Lack of provider knowledge in chronic & complex issues that affect special needs population Lack of provider empathy Inadequate care and treatment of chronic-complex issues
9. How can we assure access to information for youth and young adults, and their families in funding options and transition to adult healthcare providers?	Action could be immediate, but more so a future action if money and technology allows for ongoing monitoring	<ul style="list-style-type: none"> No progress towards the current transition issue

Information Sharing

Strategic Issue	Immediate or Future Action?	Consequences
1. How do we adapt to continually changing technology?	Both: ongoing	<ul style="list-style-type: none"> Missed opportunities in improved care Decrease in delays and cost savings

Strategic Issue	Immediate or Future Action?	Consequences
2. How can pediatric and adult health care providers ensure effective communication in regards to their patients' medical history and background?	Immediate	<ul style="list-style-type: none"> Lack of understanding in regards to treatment of patients' chronic condition for both the patient and their families
3. How can medical staff ensure better coordination and communication in the inpatient vs. outpatient setting beyond medical record information?	Immediate	<ul style="list-style-type: none"> Medical errors due to a lack of communication between settings
Manpower Development		
Strategic Issue	Immediate or Future Action?	Consequences
1. How do we increase the number of adult health care providers?	Both immediate and future: training in medical schools regarding the need	<ul style="list-style-type: none"> A continued shortage
2. How do we ensure that we have an adequate number of trained Primary Care providers for the Youth/Young Adult population?	Immediate Action: Survey to determine the current availability with program. There needs to be adequate training for pediatric and family practice providers.	<ul style="list-style-type: none"> Fragmented, inadequate medical care Increased costs, in addition to increased mortality and morbidity rates
3. How will transition systems accommodate the growing Hispanic/refugee population which has cultural and linguistic needs?	Immediate	<ul style="list-style-type: none"> Suboptimal care. Not meeting regulatory agency requirements.
4. How can we increase the availability of competent, willing and adequately reimbursed adult healthcare providers?	Future	<ul style="list-style-type: none"> Diminished access to quality care for the growing youth and young adult with special health care needs population
System Design/Development		
Strategic Issue	Immediate or Future Action?	Consequences
1. How can we provide a standard approach to transitioning planning across the community?	Immediate	<ul style="list-style-type: none"> Lack of competency for pediatric providers. Transition confusion?

Strategic Issue	Immediate or Future Action?	Consequences
2. How can Health Navigators be utilized to assist in the transition process?	Immediate	<ul style="list-style-type: none"> Lack of understanding from the patients and their families Longer, more difficult transition process
3. What is needed to ensure a successful healthcare transition for children/young adults with special health care needs from the pediatric to adult health care system?	Needs immediate action for those aging into adulthood.	<ul style="list-style-type: none"> Health care needs not being addressed will lead to increased morbidity and mortality rates.
4. How do we initiate medical home projects for our patient population?	Needs immediate action for those aging into adulthood.	<ul style="list-style-type: none"> Health care needs not being addressed will lead to increased morbidity and mortality rates.
5. How can adult healthcare physicians be motivated/recruited to accept transitioning patients?	Needs immediate action for those aging into adulthood.	<ul style="list-style-type: none"> Health care needs not being addressed will lead to increased morbidity and mortality rates.
6. How can we effectively use current medical providers and community health centers/health departments to provide Primary Care transition care and identify those Youth/Young Adults that require referrals to specialty centers of excellence?	Training Monitoring of accurate referrals Use outreach AHEC program (communicate/coordinate with health centers)	<ul style="list-style-type: none"> Lack of direction to proper care Patients are not fully benefiting from available services
7. How can we determine whether Hillsborough County could be a pilot for the Medical Home project?	Immediate	<ul style="list-style-type: none"> Loss of opportunity to pool resources
8. How do we ensure that there is continued support for people with disabilities as they achieve results in independence/self-sufficiency?	Immediate: Study issue to create plan	<ul style="list-style-type: none"> Loss of any gains (investment) towards the efforts of self-sufficiency

System Partners		
Strategic Issue	Immediate or Future Action?	Consequences
1. How can we ensure better coordination and communication for the youth and young adult population who are involved among multiple systems (i.e. Juvenile Justice, mental health, Child Welfare, etc.)?	Immediate	<ul style="list-style-type: none"> • Confusion between multiple systems. • Delayed delivery of services
2. How can the school system be more participatory in accessing transition status?	Future: needs more navigation with school systems	<ul style="list-style-type: none"> • No change
3. How do we develop a system that includes patient-to-patient advocacy, support, mentoring and coaching?	Immediate	<ul style="list-style-type: none"> • Loss of opportunity for existing resources
4. How do we raise stakeholder awareness to provide support for these efforts?	Both Immediate and future: long-term and ongoing	<ul style="list-style-type: none"> • The plans will die after the grant ends
5. How do you ensure availability of individual client/patient advocates?	Initiate planning and understanding of existing programs	<ul style="list-style-type: none"> • Individuals not receiving appropriate services on a timely basis resulting in unnecessary hospitalizations, incarcerations, and other expensive, negative alternatives
6. How can the guardianship process be improved including cost, education/awareness, efficiency and protection of individual rights?	Both	<ul style="list-style-type: none"> • Delays, or lack in care and treatment • Exploitation of resources and violation of individual rights

Wrap Up and Next Steps

Three members indicated that the next meeting date created a conflict due to Hillsborough County School's Spring Break. Members not in attendance will be surveyed to determine if a date change is needed. Next meeting will focus on prioritizing strategic issues and beginning the development of goals and objectives around the issues.

HillsboroughHATS Coalition
April 12, 2010
4:00 - 7:00 p.m.
Children's Board of Hillsborough County

Agenda

4:00-4:15	Roll Call	Teresa Kelly Coalition Facilitator
4:15-4:30	Review of Activities to Date	Teresa Kelly Coalition Facilitator
4:30-5:45	Prioritization of Strategic Issues	Teresa Kelly Coalition Facilitator
5:45-6:45	Goals and Objectives	Teresa Kelly Coalition Facilitator
6:45-7:00	Wrap-up and Next Steps	Teresa Kelly Coalition Facilitator
7:00	Adjourn	

Please note: Next Meeting Date: May 10, 2010 at Shriners Hospital Auditorium

**Meeting Summary
HillsboroughHATS Coalition Meeting
Children's Board of Hillsborough County
April 12, 2010
4:00-7:00 p.m.**

Members in Attendance:

Glenn Brown
Robert Buzzeo
Melanie Hall
Martha Kronk
Karalee Kulek-Luzey
John Mayo
Kris Millrose
David Plasencia
Lynn Ringenberg
Dondra Smith
Diane Straub
Federico Valadez
Joane White
Laurie Woodard

Others in Attendance:

Carla Gayle
Janet Hess
Teresa Kelly

Roll Call: 14 members present

Review of Activities to Date:

Teresa Kelly provided an overview of the work done to date and explained the work for this meeting would include strategic issue clarification, prioritization of efforts and development of objectives for each strategic issue.

Strategic Issues

Teresa Kelly reviewed the 36 strategic issues developed at the March meeting and presented four issues she suggested as representing the main topics indicated. The issues were presented and revised as follows:

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?

2. How can we effectively use current medical providers, community health centers, and the health department in providing primary, specialty and inpatient care transition identifying those Y/YA that require referrals to specialty centers of excellence?

3. How can we affect policies of payer sources and to recognize the specific issues around health transitions?

4. How can we ensure better communication and collaboration among multiple systems (education, juvenile justice, child welfare) in developing a transition system?

PEACH Prioritization

An overview of the PEACH (Popular Empirical Assessment of Community Health) process was given. Participants worked through three sessions of PEACH including education, advocacy/policy change, and system design with the following results:

Education	Healthcare Providers	Community Partners	Patients	Patient's Family	General Public	Total
Cultural Competency	96	17	11	5	1	130
Transition Process	205	88	121	47	1	462
Specific Medical Condition(s)	20	13	2	1	2	38
How to access and pay for care	210	43	210	35	3	501
Raise awareness of transition issues	22	4	35	21	6	88
Total	553	165	379	109	13	1219

Results: Areas where most education efforts should be focused: How to pay for care and education on the transition process. Patients and Healthcare providers have the largest role in this effort.

Policy/Advocacy	Healthcare Providers	Community Partners	Existing Advocacy Groups	Patient/Patient's Family	General Public	Total
Improving reimbursement for providers	190	82	140	4	4	420
Establishing Hillsborough County as pilot Medical Home site	123	167		16	1	307

Policy/Advocacy	Healthcare Providers	Community Partners	Existing Advocacy Groups	Patient/Patient's Family	General Public	Total
Continuing support services after age 21 in Medicaid	113	8	175	3	2	301
Improving transportation options/payment		16	15	22		53
Expanding eligibility criteria for other support services beyond current requirements (income, marital status, etc.)	71	10	117	21		219
Total	497	283	447	66	7	1300

Results: Advocacy/policy change efforts surrounding reimbursement and establishing Hillsborough County as a pilot site for medical home model were the primary areas of focus for advocacy and policy change. Health care providers and existing advocacy groups were the primary drivers of the activity.

System Design	Healthcare Providers	Community Partners	Payers	USF Medical School	AHEC	Total
Train providers in developmental approach for transition	91	72	2	52		217
Develop information sharing model/technology	51	12	31	52		146
Build a comprehensive network of providers	400	22	155	8		585
Incorporate health navigator/advocates/peer mentors in the system	210	3	65		20	298
Physician to Physician mentoring	34		12	2		48
Total	786	109	265	114	20	1294

Results: Building a comprehensive network of providers and incorporating some form of navigator/patient advocate/peer mentors into the system were the most important activities. Healthcare providers and payers were seen as the key players in accomplishing these tasks.

Formulation of Objectives

Carla Gayle provided a definition of objectives. Using the SMART principle (Specific, Measurable, Attainable, Relevant/Realistic, and Timely) as a guideline she discussed both process and outcome objectives.

Following the introduction to objectives, participants were asked to develop objectives for each of the strategic issues. During the formulation of objectives the participants decided to collapse strategic issue #2 into issue #1 leaving three strategic issues to formulate objectives around. Some action steps were also identified during the process and have been noted as such.

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: 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.

Action steps: resource mapping; Identify expertise and roles within the network (specific populations served)

Objective 2: Identify gaps in health transition education tools for providers and patient families (target population) prior to providing a comprehensive education plan.

Action step: Review existing tools

Objective 3: Determine appropriate mentor/advocate model for transition services in Hillsborough County.

Action step: Review current mentor models including advance prementoria and paraprofessional models.

Objective 4: Encourage pediatricians to adopt health transition policies in their practices.

Objective 5: Develop a method to enhance communication (clinical tools) between primary care, pediatric care and adult care providers.

Action Steps: Explore best practices; Explore possibilities for improving accessibility to medical records

Objective 6: Establish transition guideline algorithms for patients and/or their caretakers.

Objective 7: Educate current health care providers, community health centers and the health department on the need to provide primary care and identify youth and young adults who may need referrals to centers of excellence.

2. How can we affect policies of payer sources and to recognize the specific issues around health transitions?

Objective 1: Identify current advocacy/policy change activities currently in process.

Action Steps: Identify advocacy organizations related to reimbursement issues to provide concrete support; monitor the Florida Pediatric Society's suit against the State of Florida, and other pertinent legislative issues (Medicaid); identify community partners and stakeholders

Objective 2: Review and define the levels of service in medical home models in regards to reimbursement (how are the services being provided and funded?)

Objective 3: Educate legislators on the health care transition process

3. How can we ensure better communication and collaboration among multiple systems (education, juvenile justice, child welfare) in developing a transition system?

Objective 1: Engage representatives from stakeholders (children's committee, project connect, etc.) in the transition process.

Action Steps: Identify stakeholders, Identify data and information to share among groups

Objective 2: Explore the feasibility of using Developmental Evaluation Intervention Teams model on an individual level.

Objective 3: Explore options to coordinate with the IEP process with Health Transition process.

Wrap Up and Next Steps

The next meeting will be May 10th at Shriners Hospital for Children - Tampa auditorium from 4:00 to 7:00 p.m. Members were asked to spend some time thinking about action steps under each objective as preparation for the next meeting. Action steps will be finalized, and discussion of how the coalition will move forward will be held.

HillsboroughHATS Coalition
May 10, 2010
4:00 - 7:00 p.m.
Shriners Hospital Auditorium

Agenda

4:00-4:15	Roll Call	Teresa Kelly Coalition Facilitator
4:15-4:45	Where do we go from here?	Janet Hess Project Director
4:45-6:45	Action Steps Development	Teresa Kelly Coalition Facilitator
6:45	Wrap-up	Teresa Kelly Coalition Facilitator
7:00	Adjourn	

**Meeting Summary
HillsboroughHATS Coalition Meeting
Shriners Hospital Auditorium
May 10, 2010
4:00-7:00 p.m.**

Members in Attendance:

Joanne Angel
Glenn Brown
Maria Gieron
Martha Kronk
Karalee Kulek-Luzey
John Mayo
David Plasencia
Jamie Parker
Lynn Ringenberg
Dondra Smith
Diane Straub
Joane White
Laurie Woodard

Others in Attendance:

Janet Hess
Teresa Kelly
Kathey LaRoche

Roll Call: 13 members present

Where do we go from here?

Janet Hess led discussion on the continuation of the coalition's efforts. Phase 1 is almost complete and the group needs to decide how they wish to move forward to begin addressing the issues in the plan. Members were asked to think about what type of mechanism should be in place such as subcommittees/workgroups reporting back to the entire coalition on a less frequent meeting cycle.

Janet invited all members to sit in on a conference call on May 25th at 11:00 a.m. with the Statewide Health Care Transitions Task Force.

In addition, Janet indicated that approximately \$10,000 would be available to each coalition to continue their work. She asked the group for guidance on how that money should be allocated. Additional discussion on issue was held following the development of action steps.

Action Step Development

Teresa Kelly provided the objectives to each member and worked with the group to determine when work for each objective should begin. Results were as follows:

Months 1-3

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.

Objective 1-2: Identify gaps in health transition education tools for providers and patient families prior to providing a comprehensive education plan.

Objective 2.1: Identify current advocacy/policy change activities currently in process.

Objective 3.1: Engage representatives from stakeholders (children's committee, project connect, etc.) in the transition process.

Months 4-6

Objective 1.3: Determine appropriate mentor/advocate model for transition services in Hillsborough County.

Objective 1.6: Establish transition guideline algorithms for patients and/or their caretakers.

Objective 2.2: Review and define the levels of service in medical home models in regards to reimbursement (how are the services being provided and funded?)

Objective 3.2: Explore the feasibility of using Developmental Evaluation Intervention Teams model on an individual level.

Objective 3.3: Explore options to coordinate with the IEP process with Health Transition process.

Months 7-9

Objective 1.5: Develop a method to enhance communication (clinical tools) between primary care, pediatric care and adult care providers.

Objective 2.3: Educate legislators on the health care transition process.

Month 10 and later

Objective 1 4: Encourage pediatricians to adopt health transition policies in their practices.

Objective 1.7: Educate current health care providers, community health centers and the health department on the need to provide primary care and identify youth and young adults who may need referrals to centers of excellence.

Members then divided into three groups and formulated action steps for each objective and identified additional resources and other partners needed. Results attached.

Action plan will be forwarded to all members for review and comment before the final version is distributed.

Continuation of Discussion of the Future of the Coalition

Members provided input on how the coalition could continue to operate. Ideas included:

- The need for ongoing clerical and administrative support was indicated, either through a volunteer person/agency, or using some of the available funds to support the effort.
- Identify responsible parties to lead each action step, either informally or by forming a subcommittee or workgroup. Expertise in specific issues should drive the composition of the groups and outreach to new partners may be needed.
- Work on action steps could be accomplished in a number of ways including face-to-face meetings, yahoo groups, conference calls or web-based contact.
- At some point the larger group should get back together (quarterly?) to keep abreast of work being done.
- Materials developed should be reviewed by the entire group before implementation.
- Some funding should be reserved for implementation of activities.

Wrap Up and Next Steps

A draft of the action plan will be provided to all members allowing one week for comments. If there is a need to reach consensus on issues raised during the comment phase, either a conference call or e-mail exchange will occur during the last week on May.

Teresa will coordinate additional input on how to move forward following the finalization of the plan.

Evaluation Results

Surveys were provided to 23 Coalition members to assess the strategic planning process and the facilitation skills at the Coalition meetings. A total of 15 surveys were completed for a response rate of 65%.

Health Council's Skill in Facilitating the Planning Meetings

	Strongly Agree	Agree	Neutral/ Undecided	Disagree	Strongly Disagree
Staff encouraged members to participate at meetings.	80%	20%	0	0	0
Meeting materials were easy to read and understand.	60%	33%	0	0	7%
Materials were provided to members in adequate time to prepare for meetings.	60%	33%	0	7%	0
Staff had the necessary expertise to facilitate the Coalition meetings.	67%	27%	0	7%	0
The staff had a positive attitude.	93%	7%	0	0	0

Experience as a Participant in the Planning Process

	Strongly Agree	Agree	Neutral/ Undecided	Disagree	Strongly Disagree
The goals and outcomes of the project were clearly explained.	20%	60%	13%	7%	0
I understand the purpose of the planning process.	33%	67%	0	0	0
I found the meeting activities useful.	20%	73%	0	7%	0
Participation in the meetings was a valuable experience for me.	40%	47%	7%	7%	0
I plan to continue to participate in the HillsboroughHATS Coalition.	40%	40%	13%	7%	0

Comments/Suggestions for Improvement (note: Teresa was Health Council facilitator):

"I think we could have accomplished more with a more targeted process. We didn't need 5 three hour meetings. Teresa was excellent though."

"Use technology instead of paper"

"Well organized effort to bring together diverse group with the focus of smooth transition of care of children with chronic illness/disability with the additional consideration of the family."

"Continue to define tasks and keep tasks in context of overall."

"Google groups, etc."

"Great Job!"

"Teresa did a great job - (rest is illegible)"

Attachment D

Coalition Planning Tools

Community Themes and Strengths Assessment
Results from Community Themes and Strengths Assessment
Forces of Change Brainstorming Worksheet
Popular Empirical Assessment of Community Health (PEACH)

Community Themes and Strengths Assessment

Please answer the following questions to the best of your ability. Answer all six questions. Please return your responses to Teresa Kelly by February 1, 2010 via e-mail (tkelly@healthcouncils.org) or fax (727) 570-3033. Thank you!

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?

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?

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?

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

5. Describe gaps in health transition services for Y/YA that currently exist. Please list as many gaps as you can and be as specific as possible. Gaps can be disease specific, specific to a population, or a gap that exists in services to all Y/YA with chronic or complex medical needs. (Example: only one adult cardiologist who has an understanding of congenital issues; physicians are hesitant to provide care to developmentally disabled Y/YA; not enough Spanish speaking providers; little understanding of cultural issues among service providers.)

6. What assets do we currently have that can be used to improve the quality of life for Y/YA in transition?

RESULTS from Community Themes and Strengths Assessment

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?

General

- It depends upon the development level
- Issues of puberty, (delayed) autonomy, personal identity, sexuality, educational and vocational choices.
- Essential role of the family

Payment for Medical Care and Insurance Coverage

- Finding providers that accept the insurance they have who has experience with their diagnosis.
- Knowing that their health care coverage will continue without interruption.
- Knowing that they will be able to obtain the same (or equivalent) medications/treatments through their new health care coverage at a similar cost.
- Having the financial means to pay for adult medical care. When I transitioned from pediatric care (At Shriners Hospitals for Children) to adult care, suddenly my family and I were responsible for paying not only for doctor's visits, but for any medication, adaptive equipment, etc that I might need.
- Appropriate health care coverage that meets the patient's specialty services needs.
- Recipients are forced to switch to an HMO and NOT given the opportunity to change or stay with Medipass prior to the change or stay switch after CMS Network is closed at the date the recipient turns 21.
- Obtaining or maintaining a funding source for health care.

Continuity and Coordination of Care

- Knowing that they will have the same doctors or that the doctors under their new health care plan will be as good as the ones that they currently have.
- Some continuity or consistency of care so the patient doesn't have to worry more about bureaucracy than caring for his or her condition.
- Finding an adult health care system that can provide continuation of health care services i.e., primary/specialty care at a level necessary for medical condition.
- The fact that at 18 years of age quite a few services are stopped with no effective counterpart in the adult system.
- Need for true medical home that can coordinate care among specialists and services.
- To access, maintain and or improve the same level of medical care in order to be able continue to maintain or improve their quality of live, this affects every aspect of their life (ability to participate in the community, go to school, work achieve independence).
- Collaboration between CMS and AHCA before Y/YA turn 21 years old.
- Continuation of proper health care.

- Being able to transition to a managed health care plan that best fits their medical needs.

Relationship Building

- A provider who listens to them.
- Finding specialist physicians willing and interested in caring for them.
- Establishing trust with new providers.
- Feeling wanted and respected as a person.
- Giving private time to speak with the doctor regarding their concerns/issues.
- Finding a "medical home" that will meet their needs-both medical and emotional and a provider knowledgeable, compassionate and sensitive to their special needs.
- Awareness of cognitive and emotional levels of the patient

Education/ Empowerment

- Honest conversation on the process of transition.
- Some sort of assistance to families as new roles as they pertain to on-going care are being defined (i.e.: parent possibly leaving role of primary person to consult regarding a procedure).
- Having a list of contact information of competent adult physicians that have an understanding of their diagnosis. Often times Y/YA and their families don't know which physicians will be best equipped to take on their patient case.
- Knowing their diagnosis/disease/illness including symptoms and management thereof.
- Knowing how to take their medications.
- Knowing how to make medical/dental/mental health appointments when and as needed.
- If child is cognitively able, then they should begin participating in decisions about their care.

Need for Support Services

- Resources to help them navigate how to get the things they need (i.e. medication, wheelchair, etc) which will improve their health status.
- The fact that at 18 years of age quite a few services are stopped with no effective counterpart in the adult system.
- In conjunction with this, there is great difficulty accessing what services are available.
- Reassurance that the same level of medical care and social support will be available when they become an adult.
- Collaboration between CMS and AHCA before Y/YA turn 21 years old.
- The Y/YA and their family being able to have all the necessary resources to make the best health care choices.

Eligibility for Services

- I often say the worst thing I ever did for myself was get an education and get married because I am told by insurance companies, Medicaid, etc that I have a

double income (due to being married) so I make too much money and that I am disabled but not “disabled enough” to qualify for many “perks” that may be available to others.

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?

General

- Financial stability

Payment for Medical Care and Insurance Coverage

- Freedom from financial responsibility for their child’s healthcare.
- Knowing that health care coverage will continue without interruption.
- Knowing that their child will be able to obtain the same (or equivalent) medications/treatments through their new health care coverage at a similar cost.
- Learning, or understanding insurance implications or procedures.
- Knowing where to turn to so you feel confident of the care your child will receive as an adult and figuring out how to financially cover their medical expenses.
- To keep the same insurance.
- Keeping Medipass and system that is consumer friendly for the family.

Education/Empowerment

- Guide to insurance information for transitioning youth/young adults.
- Working with family members/caregivers who have cognitive disabilities themselves and are overwhelmed by intimidating and incomprehensible demands put on them.
- Learning how roles change and how support may also change as this occurs.
- Learning, or understanding insurance implications or procedures.
- Knowledge of their child's condition.
- Feeling the child can effectively manage their own healthcare needs.
- Educational opportunities to improve health literacy.
- Teaching regarding coordination of care and how that will change as child ages out of youth services and into the adult system.
- Involvement of schools in planning for long term vocational/education needs.
- Assistance with training their youth/young adults about their disease, medications and making appointments for care.
- Families being able to let the Y/YA make more decisions in their health care as they transition into adulthood.

Continuity and Coordination of Care

- Finding providers that are knowledgeable about and eager to treat their child.
- Knowing that the doctors under their new health care plan will be as good as the ones that they currently have.
- To access, maintain and or improve the same level of medical care in order to be able continue to maintain or improve their ability to continue care for their child

and achieve the child's goal, whether that is to maintain care at home, participate in the community, go to school, work, achieve independence.

- Finding a "medical home" that will meet their needs-both medical and emotional and a provider knowledgeable, compassionate and sensitive to their special needs.
- New providers have adequate skills and training as well as compassion and needed resources.
- Having a smooth hand-off and not having to repeat everything.
- Overall plan that recognizes their child's unique situation.
- Primary Care Provider (PCP) to be able to follow inpatient and outpatient for continuity of care.
- Background in pediatrics patient training (Ex: Med-Ped program trained).
- Identify a group/provider for a family to meet before sending the patient.
- To keep the same doctor.
- The opportunity to maintain an active relationship with the Y/YA and their care coordination.

Accessibility of Care

- To access, maintain and or improve the same level of medical care in order to be able continue to maintain or improve their ability to continue care for their child and achieve the child's goal, whether that is to maintain care at home, participate in the community, go to school, work, achieve independence.
- Central location/ accessible to wheelchair/stretchers.
- Proximity to other specialists so 2-3 visits on same day.
- Transportation options.

Support Services

- Support services to families once their youth are 18, and for Exceptional Student Education, once the young adult is 22.

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?

General

- A change in thinking where we professionals would see our patients through a life cycle approach as opposed to children, then youth, then young adult.

Payment for Medical Care and Insurance Coverage

- Reimbursement equivalent to the time it takes to treat the patient.
- Knowing that the Y/YA health care coverage will continue without interruption.
- Knowing that the Y/YA will be able to obtain the same (or equivalent) medications/treatments through their new health care coverage at a similar cost.
- Helping families negotiate or understand reimbursement issues.
- Adequate funding source to cover all levels of care required.
- Appropriate funding for providing care in a medical home based practice model.

- Providers have to be more receptive to taking Medicaid and/or find ways to make health care affordable for youth who are in transition from pediatric services to adult services.
- That there is no interruption in medical healthcare insurance.
- Adult care givers need to accept Medipass as a funding source.
- Ability to pay/funding for needed services.
- Healthcare financing.

Information Sharing/Communications

- Information that is readily available to assist the providers in care and treatment of the patient.
- Pediatric providers to provide a summary and next steps prior to the first visit and the opportunity for ongoing collaboration after assuming care of the patient.
- Availability of all medical records of prior primary care provider and all sub-specialists caring for teen/youth.
- Being understanding of the families as they learn their new roles and how they may be able to leverage the support of family members.
- To have an understanding that individuals with disabilities are not all “difficult cases” and there shouldn’t be a concern of taking on their case because of the time they may take compared to “normal” patients.
- Ability to quickly and efficiently communicate/share information with other providers, easier access to medical records, to be able to find up to date info about child’s condition (particularly difficult to those with rare disorders).
- Access to technology!!!!
- An “off-service” note. Pertinent past information that is important as well as current plans.
- If there are any “hot button” issues to avoid or be sensitive about.
- To be realistic with patient regarding outcome expectation/condition.
- To have updated medical records, medications and specialists involved.
- Patient and/or family to understand condition well.
- Coordination of transition efforts.
- Being an integral part of transition team.
- Providers need to be willing to assist families and schools with helping students with disabilities to transition from pediatric care to adult care.
- The proper and accurate transfer of patient records to create a successful transition from pediatric to adult health.

Care Coordination/Case Management

- Care Coordination or case management for multiple issues, including psychosocial.
- Provision for ancillary services that will assist in care coordination, such as nurse case managers.
- Opportunities and programs that coordinate and integrate services for those Y/YA with multiple needs.
- Help with case management.

- Adult providers creating a provider/patient relationship that coincides with their previous pediatric care.

Training

- A change in thinking where we professionals would see our patients through a life cycle approach as opposed to children then youth then young adult.
- Improved teaching at the medical school and residency training level in regards to care of patients with complex medical needs.

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

- Not sure or nothing seems to work - 5 responses out of 18 (28%).

Availability of providers

- Finding primary care for YSHCN when they have private funding.
- Medical specialties show competencies in knowledge regarding complex medical problems.

Payment for Medical Care and Insurance Coverage

- If the Y/YA is on SSI disability than services can continue.
- Easier if patient has Med-Waiver prior to age 18.
- Funding for youth with disabilities exists.

Coordination/Communication

- Sending of medical records/radiological studies to next provider.
- A program with a good track record of effectively dealing with Y/YA in the Child Welfare system is Connected by 25.
- Current technology exists to help with health care needs of patients with physical disabilities.
- School systems have systems in place for evaluation and planning for educational needs of youth with health care needs.
- Many patients have developed strong relationships with both primary care and specialists during their childhood years.
- CF model USF pediatric pulmonology and Adult CF Center at Tampa General
- CMS multi-disciplinary staff in place.
- CMS has a good transition program for their patients.
- Social services are the most vital component in the transition system.
- The major element of the current health care transition that seems to work well for Youth and Young Adults is the care coordination from CMS that they receive.

5. Describe gaps in health transition services for Y/YA that currently exist. Please list as many gaps as you can and be as specific as possible. Gaps can be disease specific, specific to a population, or a gap that exists in services to all Y/YA with chronic or complex medical needs.

General

- For a Child Welfare situation, a lot of Y/YAs are on the streets or in jail at 18.

Continuity and Coordination of Care

- The major gap of the current health care transition in my opinion would be the loss of care coordination once the Y/YA are no longer age eligible for the CMS program. Y/YA and their families need to be given information on how to independently coordinate their own care once they are no longer affiliated with the CMS system to maintain healthcare services and a routine that best fits their individual needs.
- There is not consistent approach to moving patients between primary care for youth and primary care for adults. No consistent mechanism for compiling the medical history of the patient other than getting this information from the patient and their family and reading the medical chart.
- Transportation needs.
- Lack of education to adult medical community about transition needs.

Communications

- Communication barrier exists between specialists and primary care. Very limited ability to group plan regarding patients, even when that patient is in an in patient setting. This seems to be due to time constraints and a reimbursement system that make it hard to get payment for this type of "work".
- Need to see the other side (pediatric/adult).
- Pediatric and adult centers need to agree on workable plan.
- Difficulty in making appointments with new providers.
- Y/YA and there families are used to a more paternalistic system of care (team approach, team clinic visits, CMS umbrella, specialty provider communication), adult providers (specialty) operate more in silos. Communication gaps between adult specialists and PCP.
- Don't treat patients like they are dumb or will break.
- Speak to the patient, not the parent (if able).

Availability of Providers

- Limited adult providers comfortable caring for these kids, insurance issues, lack of time in busy practice.
- Very limited as to who treats chronic or complex medical diagnosis and there is no "one area" to go for the information.
- There is a lack of primary care specialists to transition to in both the private sector as well as in the university training programs. This seems to be due both

to inadequate training as well as low payments from the insurance industry and Medicaid.

- Disparity and lack in communities for specialty services.
- Lack of Medicaid Physicians
- Most do not want to take Medicaid
- Medipass specialty providers for adults are very limited w/o support from AHCA.
- Very few primary care physicians who are willing to take care of this type of patient. The ones we have referred to will take a few and then refuse anyone else.
- The resources just don't exist for adults with special medical needs.
- Not many doctors accept Medicaid, hardly any specialty providers accept Medicaid. Many will not see children with complex or rare disorders.
- Lack of desire in adult provider network to take care of young adults who have chronic medical and/or developmental needs - comfort level is in pediatric specialists not adult specialists for many childhood conditions.
- Adult neurologists are hesitant to see patients with CP and other developmental disabilities.
- Limited adult sub-specialists for consultation.
- Not a solid knowledge of how to care for chronic or complex medical diagnosis.
- Adult medical system is skewed to specialists so biggest gap is in general practice or primary care clinic receiving a Y/TA from their existing medical home.

Cultural/Linguistic Issues

- Not enough Spanish speaking providers-1/3 of our patients are Spanish speaking-even when they speak English-conversationally, they often do not understand.
- Language barriers-Spanish.
- Cultural awareness.
- Not enough Spanish speaking providers.
- Cultural barriers.

Payment for Medical Care and Insurance Coverage

- Type of insurance can limit which providers will treat patients-may not get to see provider with the most expertise.
- Financial incentives are lacking.
- Finances not there.
- Change in benefit package in Medicaid when client turns 21 - unable to have funding for services that were previously considered medically necessary, i.e. nursing care in the home.
- Medicaid coverage stops and Medicare coverage may not pick up coverage for certain medical conditions (unless it affects the persons ability to work).
- Lack of affordable medical care for youth with disabilities to transition to in terms of the adult medical care world.
- Limitations for health care funding, and identification of appropriate resources.

- Adequate funding for adult primary care.
- Once patient turns 18 Medicaid does not cover the same services even though the patient continues to have the same chronic medical issues (Ex: nursing home is not covered). This can create a huge problem/crisis for families.
- Med-Waiver needs to get patients off of waiting list before they turn 18.

Support Services

- Support services are not available like they are for pediatrics (for example, no more CMS, social worker's in Doctor's offices, no child life in hospitals).
- Families need Guidance on how to complete guardianship-no resources for this.
- Limited social workers in private sector.
- Case management expensive-who pays.
- Lack of education to adult medical community about transition needs.

Developmental Issues

- Little acceptance and toleration for that group from 18 to about 23. Especially in a Mental Health setting.
- Pediatric providers are focused on developmental milestones, social issues, educational/vocational goals and challenges and the importance of improving functional status throughout childhood. Adult providers are more concerned about disease management. Developmentally delayed patients may still have potential to improve physical, cognitive, and social functioning as young adults.
- Difficult years for teens/young adults.

Examples

- Two different neurologists refuse to accept a new client because she has a diagnosis of a rare disorder.
- Client needs an evaluation for Baclofen pump but can not find a surgeon that accepts Medicaid.
- Client requires emergency gallbladder surgery and can not find a surgeon that accepts Medicaid; parent had to pay out of pocket.
- Client has an insulin pump and can not find a doctor that has equipment to download information from the pump.
- Client is on a ventilator has been in the ICU but is stable, for 9 months parents have not found a pulmonologist willing to release client to home care even though all services required are in place.

6. What assets do we currently have that can be used to improve the quality of life for Y/YA in transition?

Access

- Urban setting allows for easier transportation.
- Excellent pediatric programs for YA with special care needs.

Technology

- We have advances in technology that can speed up communication, access, sharing and organizing medical information for both providers and families.
- State of the art conferencing technology exists.
- Move towards universal electronic health records will help in communication.
- Social networking technology
- We have advances in technology that can speed up communication, access, sharing and organizing medical information for both providers and families.
- EHR capability and possible interconnectivity in the future (ER, specialists, Medical Home provider)

Institutions

- Medical school
- Regional referral centers
- School District
- Local university system is better equipped to take lead in this type of care than standard private care systems.
- USF Health has a medical home for Y/YA in transition that is not being used.
- Vocational Rehab.
- Possible partners in service and education: USF, COPH, HCHD.
- A successful CMS (Children's Medical Services) model that could be expanded to care for adults.
- More resources for those that are trying to be contributing citizens in their community.

Personnel

- CMS personnel-nurse coordinators, social worker, nutritionist.
- There seems to be an adequate number of primary care providers in Hillsborough County.
- Refer patients to a psychiatrist.
- Many pediatric providers who are willing to "hold on" to their patients until they feel ready to release them.
- I think we have many more professionals aware and sensitive to this issue. The next step is what we are doing now, which is a call to action. Support and advocacy groups such as NAMI are becoming aware of the need to focus on the population also.
- Large group of primary care providers in our community health centers already caring for a diverse population with complex medical problems.
- Emotional bonds are developed between families and health care providers.

- We utilize in CMS and Shriner's-disease specific Care Coordinators that develop an expertise in transition issues for their specific patient populations.

Payment for Medical Care and Insurance Coverage

- Safety net of County insurance program.
- Hillsborough County Health Care Plan - probably being under-utilized for this population.
- CMS to age 21
- Social Services help grants to obtain DME that is not covered by insurance and a nurse coordinator who assists families in need.

Additional comments provided by respondents

A Personal Perspective:

I mentioned in our first meeting that I was told by an ex governor of FL that, "Typically people in wheelchairs are not smart enough to go to college so we don't worry about you." I was also told by my insurance company (BCBS) to commit insurance fraud to get a home health nurse to come to my place of employment to help me with the restroom once per day. I was asked if I needed catheterized or wound care. I said no. The only way BCBS would pay for this was if I needed one or both of these things. When I described that all I need is for someone to help me undress and transfer I was told to tell the agency that I need one or both of these things and then when the aide gets to me, tell her the truth. When I refused to do so and asked what other options I had, I was told to wear Depends, go to the bathroom in that and when I got home at night have my husband change me. When this is the kind of help that insurance companies are giving you, you don't know where to turn.

I used to have Vocational Rehabilitation, whom did wonders for me. Paid for whatever my scholarship didn't for college, paid for numerous vans to be adapted, have provided me with adaptive equipment for my home, etc. I was told once I entered the working world that VR would still assist on the big ticket items, like adapting a van. Recently I was told that because of what I make, which in the big picture of adaptive equipment is not much, and the fact that I am married, they can no longer help me.

So, the help that is needed is giving Y/YA the guidance they need for healthcare as well as being as successful and independent as they can. Stop the double standard. If I hear, yes you're disabled, but not enough to get help or that you make too much to get help, I will scream!

My experience with doctors has been this: I do not even mention I have a disability when I sign up with a new doctor. If I am going to someone for something that has nothing to do with my disability, I don't want them to focus on the fact that I do. I have had some older doctors try and tell me that I was having acid reflux problems because I am high risk from my "condition". He didn't even know what "my condition" was. He saw I was in a wheelchair and he made his assumption.

Elements to consider in a Transition Model

Models of pediatric care that can be replicated for transition:

- Patient/parent advocacy
- Care Coordination

Must be "top driven" as valuable to our society/citizens in Tampa Bay

From a Medicaid perspective there are several ways to access information that will allow the Y/YA to transition into a health care plan that will best fit their needs. There are also Medicaid waivers like the Aging Out Waiver, APD Waiver, Brain and Spinal Cord Injury Waivers. Many of the waivers have limited enrollment and/or waiting lists, but might be an option for some recipients. Care coordinators should have access and be able to guide Y/YA and families to the resources that they need.

Program models can be: disease specific

- Subspecialty model
- Adolescent health model
- Primary care model

Pediatric Model	Adult Care
Family Oriented Developmental aspects considered More help with treatment regimen More trainee supervision Paternalistic	Individual focused Specifically focused on health Less communication with social service or workplace More accepting of treatment refusal Less trainee supervision Shared treatment decisions

Forces of Change Brainstorming Worksheet

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, 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.

What Kind of areas or categories should be included?

Be sure to consider any and all types of forces, including social, economic, political, technological, environmental, scientific, legal and ethical.

How to Identify Force of Change

Think about forces of change-*outside of your control*-that effect the local public health system or community.

- What has occurred recently that may affect our local health transition system or Y/YA with disabilities and chronic medical conditions?
- What may occur in the future?
- Are there any trends occurring that will have an impact? Describe the trend.
- What forces are occurring locally, Regionally, Nationally?
- What characteristics of our State or local area may pose an opportunity of threat?
- What may occur or has occurred that may pose a barrier to achieving the shared vision?

Instructions:

Prepare a list of forces of change you feel are relevant to health transition and bring to the March 8th meeting at Shriners Hospital.

Popular Empirical Assessment of Community Health (PEACH)

Community participation is a crucial part of community health planning, but it is often hard to get or impossible to quantify. By using an interactive methodology called the Popular Empirical Assessment of Community Health (PEACH), qualitative data can be captured in a quantifiable way, allowing for direct integration of community input into health assessments and the development of health policy.

PEACH was developed by The Health Councils to capture the qualitative data provided by the community. PEACH is an interactive process that allows qualitative data to be captured in a quantifiable way. PEACH uses a flexible ranking methodology to ask for information from the community on topics ranging from priority health issues; to areas of unmet need; to how scarce resources should be allocated; to the role many agents should play in expanding access to care.

This highly interactive process converts individuals' descriptive explanations of an issue or problem to quantifiable data. PEACH is conducted during community-based meetings and allows all present to rank five subjects on five variables using a 5 x 5 pocket grid. PEACH can be used in any setting in which a group must prioritize the issues or narrow the scope of focus for a project. The prioritization process serves as the foundation of the strategy development exercise, allowing the participants to translate their decisions into action steps.

Additional information can be found on our award winning conference poster located at: http://healthcouncils.org/html/documents/PEACHPROOF6_004.pdf. The Health Council offers training on how to use PEACH. Contact Elizabeth Rugg at 727-217-7070, ext. 23 or via e-mail at erugg@healthcouncils.org to discuss your specific needs and technical assistance/training fees.

Attachment E

Membership Lists

**Steering Committee
HillsboroughHATS Coalition**

Steering Committee Member List

Joanne Angel, RN
Regional Nursing Director
Children's Medical Services- Tampa Bay

Janet Hess, MPH
Coordinator
Florida Health Care Transition Initiative
USF Dept. of Pediatrics, Adolescent Medicine

Martha Kronk, RN
Director of Care Coordination
Shriners Hospitals for Children-Tampa

Kris Millrose
Social Worker
USF Dept. Of Pediatrics, Adolescent Medicine

Julie Perez, RN
Nursing Supervisor
Children's Medical Services - Tampa Bay

Diane Straub, MD
Chief
USF Dept. of Pediatrics, Adolescent Medicine

Laurie Woodward, MD
USF Physicians Group

HillsboroughHATS Coalition Member List

Vicki Adelson
Hillsborough County Health Plan

Cheryl A. Reed, MD
Pinnacle Health Group

Joanne Angel, RN
Children's Medical Services-Tampa Bay

Lynn Ringenberg, MD
Tampa Family Health Centers

Glenn Brown
Children's Board of Hillsborough County

Bruce M. Schnapf, DO
USF Dept. of Pediatrics

Robert A. Buzzeo, MD
Pediatric Healthcare Alliance

Dondra Smith
AHCA - Area 6 Medicaid Office

Maria Gieron, MD
USF Dept. of Neurology

Diane Straub, MD
USF Dept. of Pediatrics

Melanie Hall
Kids Healthcare Foundation

Federico Valadez, Jr., M Ed
Project 10

Douglas A. Holt, MD
Hillsborough County Health Department

Joane White
Children's Medical Services

Martha Kronk, RN
Shriners Hospitals for Children-Tampa

Laura B. Williams, PhD
USF Diabetes Center

Karalee Kulek-Luzey, MD
Pediatric Healthcare Alliance

Laurie Woodard, MD
USF Physicians Group

John Mayo, MA, LMHC
Success 4 Kids & Families

Kris Millrose
USF Dept. of Pediatrics

Tom Papin
Hillsborough County Children's Services

Jamie Parker
Consumer Advocate

Daniel J. Plasencia, MD
St. Joe's Complex Conditions Clinic