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

Members in Attendance:

Joane 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 Hillsborough HATS. At the conclusion of each group presentation, the coalition worked together to come up with one vision statement.

Vision Statement:

The Hillsborough HATS 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