

PanhandleHATS Coalition
February 22, 2010
4:00 - 7:00 p.m.
Children's Medical Services Building

Minutes

4:00-4:15 Roll Call: 13 members present. Hannah Ross, Amanda Marwitz, Denise Adams, Dr. Blanchard, Dr. Northup, Treasure Livingston, Janet Hess, Dr. John Reiss, Terri Justice, Wendy Altman, Susan Coleman, Colleen Foley, Mary Matthews,

4:15-4:30 Hannah refreshed the PanhandleHATS mission, goal for this meeting and where we are in the MAPP process.

4:30-5:45 **Community Themes and Strengths questions were address by the group. ** Notes on the questions and answers are provided additional to the meeting minutes. The group came to an agreement, once Drs. Blanchard and Northup explained our vision can be created from the exercise now that we are truly seeing gaps we have in place currently. Dr. Reiss explained the state status of transition along with GAPS nationally as well. He helped guide us through each question to drill down a bit so that we get a complete picture

5:45-6:30 **Gap Analysis: the group agreed to create Vision from Gap Analysis and provide versions of it for the group to agree on as action steps for our next meeting. Dr. Reiss agreed with the group that creating the vision as we unfolded the need will help gain the clarity for the goals for the coalition in months to come.

6:45-7:00 Wrap-up and Next Steps: we discussed the Youth/Young Adult Health Status Assessment which will answer the questions, “How many youth ad young adults with disabilities or special health care needs live in our community?”, “What are the characteristics of young people in our area?”, “What special services are utilized?” and “What are important indicators and performance measures for health care transition?”

7:00 Adjourn: Please note: Next Meeting Date: March 8

Opinion's from Meeting 3

Question 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?

- Few physicians have experience with cardiology and cystic fibrosis
- 21 years limits
- Transportation, specialist
- Volume of care expanding because their growing
- Education
- Funding source when loosing Medicaid
- Isn't an organized effort
- Relationship for years with pediatrician
- Retrain next physician
- How to get insured when on their own

Question 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?

- Bigger system of adult care providers
- Compliance is an issue
- Maturity issue to understand what it takes to care for self
- Continuing role as a parent
- Functional issues with pregnancy/diabetes
- Health insurance for child
- Finding a provider if not close to home
- Academic setting
- sense of independence for PT's
- roles of parents/families similar to PT's
- education- University primary care providers

Question 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?

- referral system in place
- health care reform
- CEU's in place for medical management with young adults
- Primary care providers to play a more active role
- Reaching out to medicine
- Adult medical services
- Demonstration areas

- Keep people from going to ER
- Technology?

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

- CMS model, a medical home even after graduation of pediatrics
- Proactive group meetings
- Ongoing communication
- Adult providers
- First call for help
- Expertise of knowledge base
- Partnerships
- Used to having limited resources
- Federal Quality health centers
- Dialog

Question 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.)

- School nurses/university care
- Drug free policy
- Technology glucose meters on computers, communication by email, CMS-role in state, telemedicine
- Medical genetics
- Continuing education for adult physicians
- Compliance
- Environment awareness
- Legal guardianship
- Insurance issues
- Continuity of care
- Case managers in place
- Functional issues
- Culture shock
- Brochure for resources
- Multidisciplinary
- Independent living
- Lack of trained providers and willing providers

6. GAPS Assessment

Continuing education for adult physicians

- Compliance
- Environment awareness
- Legal guardianship
- Insurance issues
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Lack of trained providers and willing providers