

**Children's Special Health Services (CSHS)  
Family Advisory Council Meeting Minutes  
May 19, 2007**

**Welcome/Introductions/Announcements:**

Tammy welcomed the following individuals to the meeting:

Present from the Family Advisory Council: Laura Roberts, Lisa Beckman, Lori Hanson, Evelyn Klimpel, Donene Feist, Twyla Bohl, Carla Peltier, and Jennifer Restemayer.

Present from Children's Special Health Services: Sue Burns, Leann Bayman, Devaiah Muccatira, and Tammy Gallup-Millner.

Tammy provided the following announcements:

- The Family Connections Conference is scheduled June 13-16, 2007 at the Best Western Doublewood Inn in Fargo, ND. Members can contact Donene for "Golden Tickets". These can be used to help pay for mileage, room and registrations costs associated with the conference.
- For members needing lodging accommodations for the meeting, staff at the Comfort Suites relayed that the government rate on weekends is one person/one bed at \$50/night and one person/two beds at \$70/night.
- The current Family Advisory Council membership list that was disseminated will be updated with new membership terms prior to the August meeting.
- Tammy reminded members of the e-mail she had sent which addressed opportunities to participate in the Rural Health Network focus groups being held across the state. There may also be an on-line survey in conjunction with this effort.

Follow-up:

The February 2007 Family Advisory Council meeting minutes were accepted as written. Items listed on the Review/Recommendation form for the February 2007 meeting were reviewed. Tammy relayed that CSHS would pay Twyla Bohl's costs to attend the National Family Voices Conference May 2007.

**Updates:**

National Update

Tammy relayed that for FY 2007, the Maternal and Child Health Block Grant has been funded through a continuing resolution. A flat budget is anticipated for FY 2008. The Association of Maternal and Child Health Programs (AMCHP) held a national meeting in March but neither Kim nor Tammy was able to attend. The annual MCH Block Grant review is scheduled for August 6, 2007 in Denver.

Department of Human Services Update

CSHS Family Advisory Council Bylaws were reviewed. Members approved the change in bylaws that allowed flexibility for meetings to be held two to four times per year.

Recognition was given to Family Advisory Council members who participated in the press conference with Governor Hoeven and several legislators when Senate Bill 2326 was signed. This bill addressed the new Medicaid buy-in program and a waiver for children with extraordinary medical needs. Pictures signed by the Governor were given to Donene and Jennifer to share with their family and friends.

### **CSHS Unit Reports:**

#### Medical Advisory Council Meeting Highlights

CSHS staff provided highlights of the annual Medical Advisory Council meeting. In response, families remarked on difficulties finding providers and the need for their children to be seen out-of-state, which is sometimes denied by payers. Council members also relayed it would be beneficial to have an orthopedist on the Medical Advisory Council. Tammy relayed that Twyla attended the meeting as the Family Advisory Council designee and reported on council activities during the year. Members were informed they would receive a copy of the minutes from that meeting.

#### Review of Anticipated CSHS Service Contracts

Tammy relayed that CSHS staff were in process of initiating service contracts for the biennium. Focus areas included multidisciplinary clinics, community-based care coordination programs, family support services and medical home projects. No major changes in services were expected with the exception of a new ND medical home initiative.

#### Family-Centered Care Advice

The following issues were discussed with Family Advisory Council members;

- Expectations with family travel reimbursement – Is it unreasonable to expect families to travel on a Saturday vs. a Sunday when they have a specialist visit scheduled Monday out-of-state if it will reduce flight costs? Family Advisory Council members indicated that some expectation of reasonableness from families was appropriate. Special considerations might include emergency situations or loss of a parent’s job with the extra time off of work.
- Provision of metabolic formula to an out-of-state student – Should CSHS continue to provide metabolic formula to a student living out-of state for a prolonged period of time? Family Advisory council members indicated that it was reasonable to verify the individual was in school and to check whether in-state or out-of-state tuition was being paid on a periodic basis. Use of an authorization that would allow CSHS staff to verify information with the college might also be needed.
- Self-referrals to specialists – Should CSHS limit self-referrals when the Medical Director and Administrative staff have concerns with their frequency and appropriateness? Family Advisory Council members relayed it was reasonable to expect more involvement from the primary care provider when determining whether a specialist referral was indicated for individuals who self-refer consistently without substantiated need.

#### Involvement of Youth/Young Adults

Tammy asked for ideas on consistent ways of getting input from youth and young adults. The following suggestions were offered:

- ND Family Voices is considering starting a ND KASA Chapter.
- School for the Blind does a lot with transitioning. Ken Dockter is a potential contact at the school.

- The North Dakota Center for Persons with Disabilities advisory board used to have a young adult that participated.
- Regional transition councils may have some young adults that participate.
- Partners in Policy may know of some young adults that completed the program.

#### CSHS Claims Issue

Laura shared a recent experience she had regarding medication claims for her son related to family cost share. Tammy requested that Laura send in explanation of benefit statements from their insurance for family medical expenses over the last year for CSHS staff to review. Laura recommended that families receive more information about what is paid and what is not and that the monthly cost share be included on the Notice of Action and Financial Review forms. CSHS staff will review the Family Handbook to make sure the above information about family cost share is included.

#### **MCH Block Grant:**

The draft plan for FFY 2008 (10/1/2007 – 9/30/2008) was reviewed. Family Advisory Council members made the following recommendations or comments:

- FPM #2 – Consider contracting through family organizations for client satisfaction assessments as part of the overall quality assurance efforts within the unit.
- FPM #3 – Consider marketing implications with use of medical home terminology. It implies an institution, building or place and can be confusing to families.
- FPM #4 – Monitor families over 200% of the federal poverty level when referring and linking families that have CSHCN to available sources of health care coverage such as the new buy-in program. This would help in assessing need at higher poverty levels.
- SPM #10 – Family Voices has a Title V fact sheet and an information link to CSHS on an outreach CD that all new families receive.

Council members submitted their family participation ranking forms which are used to complete form 13 in the MCH Block Grant application.

#### **Open Discussion:**

The council briefly discussed ideas for county training topics. Families advised that staff review ways to reduce recipient liability or cost share. For the meeting in August, a report of the National Family Voices conference was recommended. Donene relayed she would share a draft of the family-centered care outcome measures being developed by MCHB and Family Voices.

#### **Reimbursement Forms/Adjourn:**

Reimbursement forms were completed and the meeting adjourned.

**Next Meeting: Saturday, August 18, 2007 from 9:00 a.m. – 12:00 noon.**