

Children's Special Health Services Family Advisory Council Meeting

Saturday, May 7, 2011 - 1:00 p.m. to 4:00 p.m. CST
Comfort Suites, Meeting Room B, 1929 Gateway Avenue, Bismarck, ND

Welcome/Introductions/Announcements

Tammy welcomed the following individuals to the meeting:

Present from the Family Advisory Council: Laura Roberts, Lisa Beckman, Evelyn Klimpel, Donene Feist (phone), Cheryl Klee, Lori Hanson, Moe Schroeder, Jennifer Restemayer, and Carla Peltier.

Present from Children's Special Health Services Division: Sue Burns, Melissa Evans, Devaiah Muccatira, Alicia Phillips, Joan Connell, and Tammy Gallup-Millner.

Tammy and other Family Advisory Council members provided the following updates or announcements:

- Jennifer handed out a flyer notifying the group about the National MPS/ML Awareness Day on May 15, 2011.
- Moe shared that the local paper featured a story on her family and Medical Home.
- Carla shared that her son will be graduating from High School this year.
- Tammy passed around a flier announcing the arrival of Kim's Hruby's baby, Briella Mae, who was born on April 30, 2011.
- The ND State Council on Developmental Disabilities 2010 Annual Report was shared with the group.
- The ND Disability Health Project report *Disability-Related Health Disparities among ND Adults and Adolescents, 2010* was shared with council members.
- Tammy referred the council to the handout entitled *Barriers to Health Care Reform* as a source of information.
- Tammy passed around the document *Possibilities: A financial Resource for Parents of Children with Disabilities*. This helpful resource is available from the Pacer Center on the following link: www.pacer.org/publications/possibilities/
- Devaiah announced that the Title V Needs assessment document is complete and is available on the following website link: <http://www.ndhealth.gov/cshs/cshs.html>. Donene requested it be sent to her for inclusion on the Family Voices website.

Follow-up from the March 2011 Meeting

The March 5, 2011 Family Advisory Council meeting minutes were accepted as written.

Items on the Review/Recommendation Summary form for the March 5, 2011 meeting were reviewed with council members. The MCH 75th slide show and Life Course game will need to be addressed at a future meeting. Donene and Evelyn relayed they had contacted ND's Congressional Delegation to share their family story. Donene informed the council she would add the 'Family Story' link from the National Family Voices page to her local site. Tammy relayed that the final notice of grant award has not been received for 10-1-2010 to 9-30-2011 so at this point in time, cuts have not been required. The bills to address expansion of the metabolic food program and to study catastrophic diseases failed. However, effective 5-1-2011, Ornithine Transcarbamylase Deficiency (OTC) was added to the list of CSHS medically eligible conditions. Disease-specific formulas are a covered service for applicable conditions when families are eligible at 185% of the Federal Poverty Level (FPL). Tammy relayed that to her

knowledge, state law currently does not allow for families to pay the difference in formula costs if a product is needed that is not provided through the Department of Health. Melissa relayed that when travel reimbursement is provided to families who go out-of-state for medical visits, a letter explaining the requirements for travel and the need for a medical report is required before any payment is made by CSHS. The process is working as reimbursement was less burdensome for the family and medical reports were received in a timely manner in CSHS. There has been no action to date on the recommendations to help county social workers complete the medical needs and management section of the care coordination plan.

The information on agenda topics that could not be covered due to meeting time constraints in March were provided as a handout to the group.

Updates and Other Housekeeping Items

Housekeeping items

Tammy reviewed the Family Advisory Council Bylaws which were accepted without any recommended changes. Council members still felt the reimbursement amount was fair. If a youth or young adult is ever recruited for membership, Ali Karpenko from Grand Forks was recommended.

Membership terms were also reviewed. Evelyn responded she would like to renew for another two years. Carla stated she would get back to CSHS regarding her interest. Twyla was absent from the meeting so will need to be contacted regarding her ongoing participation. Membership contact information was also updated.

National Update

Tammy shared that the Block grant review will be held August 19, 2011 in Denver, Colorado. An invitation was extended to the Family Advisory Council members to either review the written block grant application or to attend the review via videoconference in the AV Rooms 210 and 212 of the Judicial Wing at the State Capitol in Bismarck. Donene and Moe were interested in participating so Tammy relayed she would provide further information to them prior to the review.

State Update

Tammy shared Legislative updates. In the Health Departments Appropriation Bill, there is a base budget for CSHS of about \$2.8 million. Some other highlights follow:

- Health Department – Major issues for MCH were vaccine funding and programs linked to health care reform. Home visiting didn't pass.
- Optional budget requests submitted by CSHS that were not included in the Governor's budget included an increase in CSHS eligibility levels from 185% to 200% of the federal poverty level, EHDI program funding, and expansion of the Asthma clinic.
- HB 2268 passed which addressed regional autism pilot programs and an interim legislative study
- SB 2212 which would have provided funded for a catastrophic diseases study failed.
- SB 2153 which would have expanded the metabolic food program failed.
- SB 2067 which expanded newborn screening to include genetic diseases in addition to metabolic diseases passed.
- SB 2298 which provided a grant program for child care providers who care for kids with special needs passed.
- SB 2135 and HB 1377 – these bills failed but would have increased Children's Health Insurance Program (CHIP) income eligibility.

CSHS Division Activities

2010 Medical Advisory Council meeting minutes were made available for review by council members. 2011 minutes will be sent out once they have been finalized.

Dr. Connell reviewed two of the larger topics from the 2011 Medical Advisory Council meeting including:

- Metabolic food program expansion - OTC was added to the covered condition list for CSHS; however, children need to be financially as well as medically eligible.
- Services reimbursed by CSHS that are provided by family practitioners, nurse practitioners and physician assistants were addressed. It was recommended that diagnostic evaluations relevant to CSHS eligible medical conditions be considered for eligibility. Consultation with an appropriate specialist still is required for coverage of treatment services once the diagnosis has been confirmed.

Sue shared a few other recommendations:

- Add hyperthyroidism.
- Approve coverage of home PT/INR Monitoring System.
- Deny coverage of auditory trainers.
- Make other housekeeping changes to the medical condition list that CSHS staff had proposed.

MCH Block Grant

Tammy asked the council to email any ideas for the draft plan activities for FFY 2012, which covers the period 10/1/2011 – 9/30/2012 as most of the work plan could not be covered in depth due to time constraints.

Tammy requested that council members turn in their family ranking sheet for family participation in CSHCN programs. Results from the combined ranking of Family Advisory Council members and Children's Special Health Services staff will be reported in the MCH Block Grant Application and shared with members at the August meeting.

Family Voices Survey of Agencies Serving CYSHCN's

Donene provided results from a new Family Voices survey that was conducted with agencies serving children and youth with special health care needs. The funding for the survey came from the Robert Wood Johnson award that Donene received. Information was collected via random phone calls to different agencies using a consistent scenario of a family in need. The purpose of this survey was to find out what was working and what wasn't working from a family perspective. The scoring was compiled by a committee after people had individually ranked the results using a Likert scale with 1 being the worst and 5 being the best. 324 calls were completed with 215 programs called. 235 were rated as responsive and 146 were rated as respectful. The average rating among all agencies across the state was 2.2. The full report entitled In Search of an Answer – Listening and Responding: North Dakota Survey of Agencies Serving Children and Youth with Special Health Care Needs is available from Family Voices. Donene relayed a "Road Map" is being worked on in response to the survey.

Family Advisory Council members made the following recommendation:

- Share the report with county social service staff at the annual county training event and have a dialogue with them regarding the results.

Reimbursement Forms/Adjourn

Reimbursement forms were completed and the meeting adjourned.

Next Meeting

The next meeting will be held Saturday, August 13, 2011 from 9:00 a.m. – 12:00 noon.