

**Children's Special Health Services
Family Advisory Council Meeting
Saturday, February 23, 2008**

Welcome/Introductions/Announcements

Tammy welcomed the following individuals to the meeting:

Present from the Family Advisory Council: Lisa Beckman (phone), Lori Hanson, Evelyn Klimpel, Carla Peltier, Jennifer Restemayer, and Twyla Bohl.

Present from the Children's Special Health Services Division: Melissa Evans, Devaiah Muccatira, Kora Dockter, and Tammy Gallup-Millner.

Guest: Brandy Mattern, Senior Nursing Student.

Tammy provided the following updates/announcements:

- Family Voices of ND received \$10,000 from the Early Childhood Comprehensive Systems grant to support a Leadership Conference, which will tentatively be held summer 2008 in Edgeley, ND.
- A ND Autism Symposium will be held March 17, 2008 from 9:00 – 4:00 at Minot State University. Contact can be made with Cathy Haarstad at 1.800.233.1737 or cathy.haarstad@minotstateu.edu for more information. Tammy relayed that CSHS has had several enquiries regarding services for children with autism and has compiled a resource list that is available to others if they are interested in the information.
- An application was submitted for Evelyn Klimpel to receive a family scholarship to attend the Association of Maternal & Child Health Programs meeting March 2008. Only 10 scholarships were available. Unfortunately, ND was not chosen this year.

Follow-up from November Meeting

The November 17, 2007 Family Advisory Council meeting minutes were accepted as written. Items listed on the Review/Recommendation form for the November 2007 meeting were reviewed with council members.

Updates

National Update

Tammy relayed she had received ND's estimated MCH Block Grant award for FFY 2008. ND is expected to receive \$1,814,527, which is a cut of \$17,839 from FFY 2007. She also relayed that efforts to expand the State Children's Health Insurance Program (SCHIP) failed although Congress did pass an extension and funding to maintain current SCHIP enrollment through March 2009. On a positive note, the Senate passed the Newborn Screening Saves Lives Act which supports education, outreach, and follow-up care for newborns with positive screening results.

State Update

Department of Health - Tammy provided an update on strategic planning activities within the Department of Health. Because CSHS is a new division in the department, staff needed to review current goals and objectives in the strategic plan to see if there was a good fit. Future

activities will include development of indicators for the “children with special health care needs” population.

Optional budget requests for the 2009-2011 biennium were discussed with Family Advisory Council members. Some of the areas discussed included: 1) medical home with emphasis on practice pilots and enhanced care coordination, 2) newborn hearing screening, 3) long-term metabolic follow-up, and 4) expansion for mental health conditions. Family Advisory Council members agreed that medical home and mental health expansion were the top priorities.

Department of Human Services - Tammy relayed that the Infant Development Program study was not addressed at the April 1, 2008 meeting of the Human Services Committee. The next meeting of the committee is tentatively scheduled for June or July 2008.

Tammy provided an update regarding the new waiver for medically fragile children, which was formally submitted to CMS on 1/11/2008. After the waiver was submitted, CMS forwarded questions which DHS staff are in process of answering. Big changes include the elimination of specialty care services and case management as an administrative activity. Other work efforts include level of need determination process, roles and responsibilities of central office and Developmental Disabilities case management staff, and development of outreach information. Pending CMS approval by 4/1/08, DHS anticipates an official start date of 6/1/08. The next Medical Needs Task Force “webinar” meeting is scheduled for 3/28/2008.

Tammy relayed that she’d talked with Curtis Volesky about the new Children with Disabilities Program, which was previously know as the buy-in eligibility option for families up to 200% FPL. The program will start April 1, 2008. County staff were trained the end of January. In February, letters were sent to about 30 families with medically needy children regarding the program. A fact sheet was also developed and a new release sent out about the new program. Family Voices is working to get the news out about the new eligibility option and hopes to provide additional information to help families. Some may need help understanding the disability determination process though the Social Security Administration/Disability Determination Services and the State Review Team. Members questioned the time it would take for disability to be determined.

Review of Outreach Materials

Waiver Fact Sheet

Family Advisory Council members reviewed the fact sheet on the new waiver for medically fragile children. Members indicated they liked the flow chart as it helped them understand the process. They also requested notification when the waiver was approved and that their comments be passed on to Medicaid staff.

Children with Disabilities Program (Buy-In) Fact Sheet

Family Advisory Council members reviewed the Children with Disabilities Medicaid Coverage fact sheet and asked that the following recommendations be passed on to the Medicaid staff:

- There is a need to educate families about the need to reapply for Medicaid because there are different income guidelines with this new program.
- Families need to balance the time it may take to apply when they may not be eligible with the importance of expressing need for the program for families at 200%-300% of the federal poverty level.

- It would be helpful to describe the actual income amount at 200% of the federal poverty level and what deductions are included to arrive at net income.

Newborn Screening Video

The video entitled “Newborn Screening – Protecting Your Baby’s Health” was viewed. The video has been mailed to various providers in the state so they can better educate parents on the importance of newborn blood and hearing screens.

CSHS Division Reports

2005/2006 National Survey of CSHCN

Data from the national survey of children with special health care needs was shared with council members. Devaiah also provided a handout from the Data Resource Center that showed how data can be used to influence policy.

Integrated Services Grant

Kora provided an update on the ND Integrated Services grant that was recently submitted by the North Dakota Center for Persons with Disabilities in partnership with CSHS. Out of the six national performance measures for children with special health care needs and their families, the grant has the potential to impact family involvement, transition, and medical home.

Review of CSHS Policies

The following draft policies were reviewed. Comments follow from Family Advisory Council members.

Acquired Brain Injury

- Therapy may be an issue – what is provided at school vs. what is determined medically necessary.

Immunodeficiency Disorders

- No comments.

Travel Reimbursement (Cost Share Reduction) Policy

- CSHS staff relayed that documentation of a visit with the medical specialist who is treating the child’s eligible condition will be needed in order for travel expenses to be used to reduce cost share.
- CSHS staff relayed that only expenses for the month that travel occurs would be included. Family Advisory Council members recommended exploring whether this could be expanded beyond one month with the possible carry-over to multiple months.
- For mileage, members agreed that map miles be used with the family’s personal car.
- Members recommended that CSHS staff also address bus, air, train, taxi, shuttle, in-town, out-of-town, etc.
- Members recommended use of state rates for meals without receipts.
- Members agreed to be consistent with Medicaid policies and reimburse expenses for the child and one parent.
- Members recommended using an established rate for lodging or base reimbursement on receipts.

- Members recommended that CSHS staff address the number of allowed days in the policy.

Open Discussion

Agenda topics suggested for future Family Advisory Council meetings included a review of the Medicaid transportation policy once it has been finalized, a review of the syndromes policy, and carry-over of the family leadership planning and discussion agenda item.

Reimbursement Forms/Adjourn

Reimbursement forms were completed and the meeting adjourned.

The next meeting is scheduled Saturday, May 17, 2008 from 1:00 a.m. – 4:00 p.m.

Jennifer Restemayer agreed to provide a Family Advisory Council report at the May Medical Advisory Council meeting.