Children's Special Health Services
Family Advisory Council Meeting Minutes
November 20, 2004

Present from the Family Advisory Council: Lisa Beckman, Donene Feist, Cheryl Klee, Jennifer Restemayer, and Evelyn Klimpel

Present from the CSHS Unit: Kora Dockter, Sue Burns, Leann Bayman, and Tamara Gallup-Millner

Present from the Medical Services Division: Dave Zentner

Present from the Department of Health: Kim Senn

Follow-up from the August meeting: Minutes were accepted and the Review/Recommendation form was distributed.

Announcements: Members were informed that no council members had indicated an interest in attending the AMCHP meeting February 2005. Members also heard about the ND Youth Disability Leadership Conference to be held June 7-9, 2005 in Minot. The conference is for youth with disabilities between the ages of 14-21 who want to discover and develop their leadership skills. For more information, members can call Dawn Olson at 1-800-233-1737 or check out: www.ndcpd.org/youth.

CSHS Program Updates:

Administration

- Budget - Dave Zenter provided information regarding the 2005-2007 budget. Medical Services requested $71 million more in general funds than a hold even budget required. With FMAP changes that are expected for the Medical Assistance program, this amount allows current programs within Medical Services to run as they currently do. It does not allow for enhancements; however, an inflation factor of 2% was included. The Governor's budget will be released in early December. Other changes may also occur during the legislative session. For CSHS, what was initially submitted was approved. Tammy relayed that CSHS has not yet received the federal grant award for FFY 2005, which started in October. Flat funding is anticipated. There are also concerns that cuts will be made in domestic discretionary funding in FFY 2006 to help deal with the federal deficit. These cuts would likely impact Title V funded programs.
- New committees with CSHS representation include: 1) DHS research workgroup, 2) DPI Transition steering council, and 3) System of Care Review Team. The latter group is looking at ways to serve children with significant medical needs who don't have a developmental disability. A medically fragile waiver, sometimes referred to as a 619 B waiver, could be considered if it was cost neutral. Family involvement was

recommended. Jennifer Restemayer requested that her name be passed on to Deb Balsdon and Terry Bohn for participation on the review team.

- Early hearing detection and intervention (EHDI) – Sue reported that Minot State University applied for another 3-year EHDI grant. Efforts will broaden beyond screening and focus on follow-up to make sure families are getting the services they need.
- Asthma legislation – Kora reported that legislation is expected regarding self-administration of emergency medications for asthma and anaphylaxis in school. She has been working with various partners around this issue. Donene suggested the Children's Caucus be involved and volunteered to contact them. Families concerned about this issue have an opportunity to provide written or oral testimony.
- Strategic planning – A bill relating to a government performance and accountability system has been recommended by an interim legislative committee. If passed, agencies would report results to the legislature. Tammy shared state performance measures for CSHS that are being monitored within DHS. Two will be reported on over time. They include: 1) the percent of individuals/families served by CSHS reporting services received met their needs, and 2) the percent of children served through CSHS with a source of health care coverage.
- CSHS Medical Director – Tammy announced that Dr. Wentz will continue as CSHS Medical Director; however, he will reduce on-site support from a weekly to every other week basis.

Specialty Care

- The new Family Handbook was disseminated. Staff will start mailing it to families effective 1/1/05.
- Leann reported on planning activities currently underway for a new Medicaid Management Information System (MMIS). Many payers, including CSHS, pay claims through this system.

Multidisciplinary Clinic

- Sue reported that it has been difficult finding orthopedists that will see youth with possible scoliosis. CSHS is seeing some "holes" in the network of pediatric subspecialty providers within the state (e.g.) pediatric orthopedists, pediatric neurologists, etc.

Health Department Report

- Kim relayed there is an opportunity for a parent to participate on the school health service guidelines committee. If anyone from the council is interested, please let Kim know. The work will be contracted through Minot State University.

Care Coordination

- Information was shared regarding the county/public health care coordinator training that CSHS sponsored. There were 34 attendees. Returned evaluations were very positive. Donene Feist, Vivian Drees, Nicole Bohl, and Jennifer Restemayer, were acknowledged as family presenters and training materials were made available for review.

- Public Health Care Coordination standards – Kora reported that CSHS and local public health unit staff reviewed program standards. In the future, changes being considered are inclusion of both short and long term care coordination supports. Short-term care coordination would likely include periodic information and referral services. Long-term supports would involve comprehensive coordination services like those currently being provided.
- Tammy informed the council of a concern voiced by a county director about program demands required of county staff, the value of the annual CSHS training opportunity, and disparity in service access between Medical Assistance and CSHS programs. State staff continue to conduct periodic site visits with county CSHS and eligibility staff to encourage linkages between programs.

Metabolic Food

- CSHS participates in a Newborn Screening Advisory Committee and will be presenting information regarding CSHS coverage of genetic services.
- Metabolic screening is an emerging national issue. Currently, there is variation in the number of conditions newborns are screened for across all 50 states. Nationally, work is focusing on a uniform panel of conditions and development of a comprehensive system. Kora obtained the following input from Family Advisory Council members:
    - Education about newborn screening should be done at the end of the second or beginning of the third trimester (28-30 weeks gestation)
    - Use fact sheets and state meetings to educate providers
    - Have an informational brochure available for parents that has been reviewed by families
    - For women that have not received adequate prenatal care, alert the hospital that an extra level of support is needed after delivery
    - Have CSHS involved in the upcoming meeting with Dr. Martsolf (geneticist)

Information Resource Center

- CSHS brochure – Sue shared an updated draft of the CSHS brochure and received the following comments:
    - Members liked the pictures and question format
    - Suggested adding “talk to your county worker about the complete condition list and information about covered services”
    - CSHS resource catalog and fact sheets from the Health Department could be added to the Family Voices website
- Public information plan – Tammy relayed that 90% of the public information plan had been completed and that a report was forthcoming. In the coming year, CSHS will focus on the toll free number, an EHDI physician survey, dissemination of needs assessment results, and implementing recommendations from the DHS public information officer in addition to other routine activities.

Data Systems Development

- Birth Defects Monitoring System Grant – Terry submitted a new grant application in October 2004, that if awarded, would improve the North Dakota Birth Defects Monitoring System.
- Tribal data meeting – Terry recently attended a meeting at the Turtle Mountain reservation to discuss data issues between Title V, Tribal Health, and Indian Health Service in the Aberdeen area.
- CSHS Needs Assessment – A handout with family satisfaction results from the CSHS 2004 Family Needs Assessment Survey was distributed. Donene recommended reviewing satisfaction levels in the Comp Care report also. Tammy relayed that the Title V planning retreat was held October 28-29, 2004. Stakeholders had an opportunity to provide input into health priorities and interventions. For the CSHCN population, three areas emerged: health system, family challenges, and access. Information provided at the Title V planning retreat was disseminated. Family focus group and provider survey results were also shared. Tammy indicated the following dissemination plan for CSHCN needs assessment results: 1) reports available via website, 2) meeting with DHS public information officer to discuss dissemination strategies within and outside DHS, 3) news release when journal article becomes available with state rankings for CSHCN's, and 4) fact sheets useful to multiple audiences.

The next Family Advisory Council meeting is Saturday, February 19, 2005.