

**Children's Special Health Services (CSHS)
Family Advisory Council Meeting Minutes
August 19, 2006**

Welcome/Introductions/Announcements:

Tammy welcomed the following individuals to the meeting:

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

Present from CSHS: Sue Burns, Leann Bayman, Devaiah Muccatira, and Tammy Gallup-Millner.

Laura Roberts, a new Family Advisory Council member, was introduced. Laura shared information about her family, including her two children with special health care needs. One of her sons was born without an iris, has glaucoma, and had a kidney removed and subsequent chemotherapy for a Wilm's tumor. The other had a congenital heart disorder, which has been fixed.

The following announcements were made:

- Tammy reminded members of the of *ND 2006 Interagency Secondary Transition Institute*, which will be held October 2-4, 2006 at the Seven Seas Inn in Mandan, ND. CSHS will be sending brochures for the institute to families served by CSHS who have transition aged children. A registration form and Institute brochure are available at the following website: <http://www.dpi.state.nd.us/transitn/index.shtm>
- The Youth Advisory Committee for the National Council on Disability is searching for new members. If anyone knows of a youth or young adult aged 16-25 who might be interested, please contact Tammy for more specifics. Applications must be received by September 14, 2006.
- *Partners in Policymaking* is a leadership training program for adults with disabilities and for parents of children with disabilities. The Arc of Bismarck is currently accepting applications for the next class of eight sessions, which will begin in October. For more information, visit the following website: <http://www.arcofbismarck.org/partners>.
- A conference entitled *Connecting the Circle: Living & Working in the Community* will be held September 19-21, 2006 at Four Bears Casino & Lodge in New Town. Concurrent sessions include various presentations on assistive technology, community living and employment related topics.

Follow-up:

- May 2006 Family Advisory Council meeting minutes were accepted as written.
- The Review/Recommendation form that resulted from the May 2006 meeting was reviewed. Corrections in e-mail addresses included on the membership list were given for Evelyn Klimpel and Laura Roberts. Tammy will update the list for the next meeting.

- Form 13 – *Family Participation Ranking* that was submitted for the FFY 2007 MCH Block Grant Application was reviewed. ND received a score of 16 out of a possible 18. Family rankings and CSHS staff rankings were very similar. Rankings were done independently and then averaged to obtain a composite score. Tammy relayed federal reviewers indicated that the state was conservative in its ranking of family member participation on advisory committees or task forces.
- Sue reviewed the draft work plan CSHS staff had developed based on recommendations obtained from the May 2006 CSHS Medical Advisory Council meeting. Although there were no particular areas of concern with the plan, Family Advisory Council members and staff shared the following:
 - Physician certification/re-certification – Many families need to go out-of-state for specialty care. In rural ND, there are not a lot of options when it comes to providers. Families often have to look hard for services and good physicians who listen.
 - It is good CSHS is working with the Health Department for outreach related to newborn screening.
 - The CSHS condition list is a way to ration care.
 - New Medical Advisory Council members include: Siriwan Kriengkrairut, Ellen Ketterling, and Thomas Mausbach. Family Advisory Council members indicated it was good to have diverse specialists and physicians from various geographic parts of the state and health care systems represented.
 - A recommendation regarding First Sounds will be added to the plan as it is finalized. A Medical Advisory Council member relayed organized medicine would likely not support any unfounded mandates for newborn hearing screening.

Updates:

National Update

Tammy relayed that the MCH Block Grant review was conducted August 7, 2006. She and Kim Senn traveled to Denver while other Title V staff connected by videoconference. This year North Dakota had three reviewers including a parent from Oklahoma. A major strength identified by reviewers was the strong commitment to partnerships/collaboration and the involvement of stakeholders and consumers. A major challenge was the state's health disparities. The grant was approved without any requirements. Reviewers recommended more content be included in the Health Systems Indicators section.

Department of Human Services Update

Tammy relayed the Budget Committee on Human Services had met May 31-June 1, 2006 and July 10-11, 2006 regarding the children with special health care needs study. The May meeting focused on the Anne Carlsen Center for Children. At the July meeting, the department provided testimony on the status of the Medicaid waiver. The Legislative Council staff provided a summary of services in surrounding states. This report was shared with Family Advisory Council members. Services offered by surrounding state programs were relatively consistent with North Dakota although numbers of children served and delivery systems varied considerably.

Tammy relayed that the Medical Needs Task Force met on May 31, 2006 and June 28, 2006. The prevalence study has been completed, a compilation of service needs initiated, and suggestions for the new waiver for medically fragile children solicited. The completed waiver application is expected to be available this fall for public comment.

Medicaid Pediatric Task Force meetings continue to be held on a periodic basis. Tammy relayed these meetings create an opportunity for providers to interact with state level staff regarding Medicaid issues. At the last meeting, attendance by providers was poor outside the Bismarck region.

Tammy notified the group that pending legislative approval, CSHS will move from the Department of Human services to the Department of Health July 2007. OMB requested the unit's budget be moved to the Health Department in anticipation of the change. Transition planning is underway.

CSHS Program Reports:

Policy Manual Update

Sections of the draft CSHS Policies and Procedures Manual were shared with Family Advisory Council members. Since the manual is being revised, input was solicited regarding the "Family Responsibilities, Family Advisory Council, and Care Coordination for Children Receiving Treatment Services" sections. No concerns were voiced with proposed changes but the following recommendations were made as changes were discussed:

- In addition to the CSHS notice of action letter, provide "cards" like MA that have the CSHS address and phone number listed.
- Make sure providers are updated with the annual financial review.
- Let county workers know that it is hard for families to ask for help. Suggest that the county worker bring up issues rather than waiting for the families to ask. Also suggest they use open-ended questions.
- Encourage county workers to explain what is covered by CSHS.
- Let county workers know that families appreciate their coming into the home and taking time to build a level of trust with them.

Public Information Update

Sue shared the new CSHS brochure, which was recently printed and thanked families for their previous input as it was being developed. Sue also reviewed the updated draft of the North Dakota Focus on Progress fact sheet. This handout will be used for presentations to help others understand systems development activities CSHS carries out on behalf of CSHCN and their families. Laura Roberts was thanked for contributing her family story in the community snapshot section of the fact sheet. Members suggested additional links but Sue relayed we were limited in the amount that could be included.

Clinic Coordinator Meeting Agenda

Families were asked for input for the September clinic coordinator meeting. Members suggested the following be addressed:

- Program sharing - learn from each other
- CSHS 101 – clinic staff may know who we are but not what we do
- Address billing process – some concerns for families
- Provide more resource information (e.g.) summer camps

Care Coordination

Tammy relayed that Grand Forks Public Health has hired a new care coordinator and that the contract with Fargo Cass Public Health was terminated effective 7/20/2006. With the recent retirement of the care coordinator in Fargo, the Public Health Unit indicated they were not interested in moving in the direction of care coordination through a medical home that CSHS is promoting.

County and Public Health Care Coordination Training Topics:

Tammy shared the draft agenda with Family Advisory Council members and relayed their previous recommendations regarding medical home, transition, and health benefits counseling would be integrated into policy sections. She also let families know that county workers consistently rank the family presentation very highly. This year we hope to have a parent of a child with cystic fibrosis share his or her family story. Cystic Fibrosis was selected as the condition was recently added to the newborn screening panel and services are available at two ND centers. Hopefully, babies will be identified sooner than what had occurred previously.

Open Discussion:

Sue shared the “Strongest Dad in the World” print story and video clip, a moving story from Sports Illustrated about Dick and Rick Hoyt. For more information, check out the following website:

<http://www.youtube.com/watch?v=f4B-r8KJhIE&mode=related&search=>

Family Advisory Council members were asked for input on future agenda topics but no topics were recommended.

Reimbursement Forms/Adjourn:

Reimbursement forms were completed and the meeting adjourned.

Next Meeting: Saturday, November 18, 2006 from 9:00 – 12:00 noon