

**Children's Special Health Services
Family Advisory Council Meeting
Saturday, August 9, 2008**

Welcome/Introductions/Announcements

Tammy welcomed the following individuals to the meeting:

Present from the Family Advisory Council: Lisa Beckman, Lori Hanson, Donene Feist (phone), Laura Roberts, and Evelyn Klimpel.

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

Present from the Family Health Division: Kim Senn.

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

- Reappointment letters for CSHS Family Advisory Council members that opted to serve for another two-year term were mailed out July 28, 2008.
- About 25-30 applications are being accepted for the second Family Leadership Institute, which will be held before May 31, 2009.
- Tammy passed around the *On the Road to Wellness – North Dakota Disability Health Project* newsletter. To receive the newsletter, e-mail kari.arrayan@minotstateu.edu or contact project staff at 1-800-233-1737. Health disparities for people with disabilities have been identified in ND. To promote fitness, use of a Wii game room is one of the exciting opportunities that has been made available through the grant.
- Nancy Martin, Coordinator of the Family to Family Network resigned effective July 21, 2008. There are concerns whether the project can be effectively administered in the Department of Social Work at UND so other options are being considered. The parent-to-parent program may shift to another family organization in the state, which most likely will be Family Voices. Laura mentioned that the University of Mary has a program where students also learn from experienced parents.
- Andrea Pena has been hired as the new Executive Director of the State Council on Developmental Disabilities.
- A \$150,000 Early Hearing Detection and Intervention (EHDI) data integration grant was received by the North Dakota Center for Persons with Disabilities (NDCPD) for the period 7/1/2008 through 6/30/2011. Goals in the grant address linkage of birth records, EHDI, newborn screening, and immunization data. Data linkage will help reduce babies who are lost to follow-up with hearing screening.
- The Rural Health Network for Family Support is looking for family members to serve as community representatives on the ND Family Support Network board. The individual must be a parent, foster parent, adoptive parent, grandparent, or sibling of a child or adult with a special health care need or disabilities who lives in ND or in a border community but receives services in ND. If interested, please contact Tammy at tgallupmillner@nd.gov so your name can be submitted.
- Tammy relayed that CSHS anticipates some upcoming staffing changes. Kora will be leaving the division to work with NDCPD on the Integrated Services Grant. Dr. Wentz,

long-time CSHS Medical Director, has asked that CSHS recruit a new medical director because of his declining health status.

Follow-up from February Meeting

The May 17, 2008 Family Advisory Council meeting minutes were accepted as written. Items listed on the Review/Recommendation form for the May 2008 meeting were reviewed with council members.

Updates

National Update

Tammy relayed that the 2009 Maternal and Child Health Block Grant application was submitted to the Maternal and Child Health Bureau and is now available for comment. A formal review of the application is scheduled for August 14, 2008 in Utah. Results of the Family Participation Ranking that was submitted with the application were reviewed. For the 2009 application, ND received 15 out of a possible 18 points. Tammy relayed that the 2009 SSDI Grant application was also submitted.

State Update

Department of Health - Tammy provided an update on the biennial budget process within the North Dakota Department of Health. The CSHS division ended up submitting three optional budget requests rather than two. The first one provides support for a ND Early Hearing Detection and Intervention Program. The second supports a ND Medical Home Initiative. The third provides additional funding for CSHS claims in the event the legislature increases Medicaid reimbursement rates for select providers based on the rebasing study that was recently completed in addition to the more typical inflationary increases. Kim Senn relayed she submitted an optional budget request that addressed newborn screening, a dental care mobile, and health services in childcare and schools.

Department of Human Services - Tammy relayed that she talked with Kathy Barchenger about the new waiver for medically fragile children. Currently, three children are enrolled, one in the Fargo region and two in the Bismarck region. Level of care has been met easily. Points for level of need have ranged from 45 to 77. A minimum of 40 points are required. The process seems to be going well and both Medicaid State Plan and waiver support services are being used (e.g., nursing care, equipment, etc.). Kathy continues to do outreach for the new program and is providing training for Developmental Disability Case Managers. It is also important that families know that only the child's income is used to determine Medicaid eligibility.

The new Children with Disabilities or "Buy-In" program was also discussed. In July 2008, 11 children were eligible. According to Curtis Volesky, implementation is going well but numbers are lower than expected. It is likely that children with high needs are already on Medicaid. He has not had much feedback from county staff or generally many questions about the program. The following points were brought up for discussion at the meeting:

- Perhaps the premium is too high or income level is too low.
- Although Family Voices is providing information and trying to get radio spots, more outreach from DHS and the counties could be helpful.
- Families may feel shame when seeking government help.
- There may be some variation between counties regarding the new program.

- It would be helpful if children who are denied SSI could be referred automatically to the Children with Disabilities or “Buy-In” program.

Deb Balsdon e-mailed Tammy and relayed there had been no action or feedback on the Infant Development Legislative Study since the January 9, 2008 meeting of the Human Services Committee. Deb indicated she was working on staffing ratio and payment issues through an optional budget request within the Department of Human Services.

CSHS Division Activities

Administration

- Tammy routed a revised membership list so the name and birth date of the child or youth with special health care needs could be added.
- The group discussed the need for a tenth member on the council such as a youth, family with a younger child served by CSHS, or other “family organization” representative. Donene relayed that Family Voices has a repository of people who may be interested. General consensus was to recruit a family with a younger child served by CSHS.
- Tammy relayed she was interested in providing opportunities for family leadership on the council. CSHS Family Advisory Council bylaws state that officers will include two co-chairpersons consisting of one family representative and one CSHS staff person. The family co-chair must be approved by a majority of the membership. Responsibilities include help in preparing the agenda, presiding over the meeting, and ensuring the Family Advisory Council fulfills its role and mission. Representation at the annual Medical Advisory Council meeting is also needed. No council members in attendance were interested in assuming a leadership role but recommended that follow-up be done with other council members to ascertain their interest. Jennifer Restemayer was recommended. Members may need to consider a bylaw change if no one is willing to assume the co-chair role.
- Sue provided a report from Utah LEND staff on clinic review recommendations. Prior to the review, quality assurance data was gathered and background information on clinic services was summarized. The goal of the review was to identify potential improvements in how clinics are provided or funded by CSHS. Some of the areas addressed during the review included the following:
 - Providers (e.g., what conditions they think are hard to manage, service contracts, recruitment issues, etc.)
 - Gaps in services after age three
 - Types of clinics that are needed
 - Clinic billing
 - Revisions to the CSHS eligible condition list
 - Recommended developmental screening tools (e.g., PEDS)
 - Potential areas of duplication
 Donene wondered whether providers have a need for in-services on family support options for their staff.
- Do to time constraints, the summary of findings from annual contract reports will be addressed at the November meeting.

Public Information Services

- Melissa reported on county site visits that have been conducted. Usually, staff target sites where there are problems or a brand new worker because of staff turnover. At the visit, a CSHS overview is provided. State staff talk about training needs and potential outreach

activities in addition to CSHS eligibility and care coordination. Information on medical conditions is often wanted. Staff try to meet with county eligibility workers and the county director in addition to the local CSHS worker. Staff have found that assessments of client satisfaction are usually not done by county staff. The most common questions received deal with dual eligibility for Medicaid and CSHS. Many CSHS workers go to the family's home instead of arranging a meeting at the social service office.

- State staff are concerned that eligibility forms are being mailed to families for completion rather than meeting with the county social service staff. Family Advisory Council members were asked whether CSHS should continue to require a face-to-face visit. Members indicated that a meeting was a reasonable expectation but that some of the paperwork such as the authorization form could be completed at home in advance of the meeting. Members agreed that the service plan should not be filled out alone and that some county staff were more helpful than others when linking families to services.
- Sue solicited comments on the draft health care coverage options pamphlet. The following feedback was given:
 - Check guidelines of care inserts and Family Voices Resource Guide as a cross check to make sure options were not missed.
 - For the section on student health plans, check the BCBS website for additional information. Include content about contacting an insurance agent or university for more information on these types of short term plans.
 - For IHS and Tribal Health, Fort Berthold has a booklet that might be helpful. St. Alexius Medical Center also has a fact sheet that admitting staff give out. Contact with Phyllis Howard and Theresa Snyder was also recommended.
 - Consider adding Vocational Rehabilitation, the Insurance Department, and various service organizations.
 - In the future, development of a fact sheet on family support programs could also be useful
- A copy of the transition mailing that will be sent to primary care providers this fall was briefly reviewed. Generally CSHS targets transition information for youth 14-21 years of age.
- Council members reviewed the draft county training agenda. Tammy relayed that staff would also conduct a “new worker” training the night before. Family Advisory Council recommendations regarding the training agenda follow:
 - For the medical condition agenda item, provide training on CSHS covered conditions (e.g., Wilms tumor) rather than on autism even though autism spectrum disorders are an emerging health issue.
 - Consider inclusion of a jeopardy game. Donene will send a copy to CSHS for review.
 - For the family story on autism spectrum disorders, consider Vicki Peterson as a speaker.
- Family Advisory Council members were asked to review the draft *State of Health in North Dakota – Children with Special Health Care Needs* document and provide comments to Tammy at the next meeting.
- Copies of the *North Dakota State Genetics Plan* were provided to council members.
- Comments were solicited from council members on the draft feedback card that may be used to help evaluate CSHS information and referral services. The following feedback was provided:

- May need to include information on the topic or kind of information that was received and about the type of problem if families were not satisfied with the information so staff knows what needs to be changed.
- Split the following question into two separate questions: “The information I received increased my knowledge about specific health-related topics and helped me find out about available services.”

Open Discussion

No other discussion items or future meeting agenda items were brought forward by council members.

Reimbursement Forms/Adjourn

Reimbursement forms were completed and the meeting adjourned.

The next meeting will be held Saturday, November 15, 2008 from 9:00 a.m. to 12:00 noon.