

**Children's Special Health Services  
Family Advisory Council Meeting  
Saturday, May 17, 2008**

**Welcome/Introductions/Announcements**

Tammy welcomed the following individuals to the meeting:

Present from the Family Advisory Council: Lisa Beckman, Twyla Bohl, Lori Hanson (phone), Donene Feist (phone), Cheryl Klee, and Jennifer Restemayer.

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

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

- Donene Feist is a finalist for the 2008 Robert Wood Johnson (RWJ) Foundation Community Health Leaders Award. Out of the hundreds of nominees, Donene was one of the top 15 candidates. A total of 10 awards will be given with a potential prize for each organization of \$105,000. A site visit by RWJ will occur this summer with winners announced early fall 2008.
- Youth and young adults between the ages of 12 and 24 are needed for the Kids as Self Advocates (KASA) Advisory Board and Task Force. Applications are due May 30, 2008 and can be downloaded at [www.fvkasa.org](http://www.fvkasa.org)
- The Division of Mental Health & Substance Abuse Services is establishing a statewide Youth Advisory Council. There are opportunities for youth and/or young adults 14-20 years of age to participate. If interested, please submit names by May 21, 2008 to Susan H. Wagner at [shwagner@nd.gov](mailto:shwagner@nd.gov) or by phone at 701.328.8941. CSHS has not been involved with this effort but may try and partner with the Mental Health & Substance Abuse Division.
- Effective May 1, 2008, the North Dakota Center for Persons with Disabilities received a three-year grant to develop a Rural Health Network for Family Support.
- Tom Wallner, long-time Executive Director of the ND State Council on Developmental Disabilities, is retiring effective July 31, 2008. Grant proposals to provide services and conduct activities for persons with developmental disabilities are being solicited with a July 31, 2008 deadline.
- May 15, 2008 was National MPS Awareness Day. In celebration of Allison Restemayer's fifth year of enzyme replacement therapy, Jennifer developed a slideshow on You Tube. It can be accessed at [http://www.youtube.com/watch?v=hivLd31\\_DYQ](http://www.youtube.com/watch?v=hivLd31_DYQ). Information is also available on Allison's Caring Bridge website at [www.caringbridge.org/nd/allison](http://www.caringbridge.org/nd/allison).

**Follow-up from February Meeting**

The February 23, 2008 Family Advisory Council meeting minutes were accepted as written. Items listed on the Review/Recommendation form for the February 2008 meeting were reviewed with council members.

## **Updates**

### National Update

Tammy relayed that the Maternal and Child Health Block Grant review is scheduled for August 14, 2008 in Utah. Donene relayed interest in seeing a hard copy of the grant when it is completed and possibly participating in the four-hour review process for North Dakota. Tammy also relayed she participated by phone in planning activities between Title V and Family Voices directors at the Family Voices Regional VIII Conference. In future, a tool to measure family-centered care may be used with agencies in ND.

### State Update

Department of Health - Tammy provided an update on the biennial budget process within the North Dakota Department of Health. Flat funded budgets are anticipated for the 2009-2011 biennium. The division did, however, submit two optional budget requests, one to support a ND Early Hearing Detection and Intervention Program and the other to support a ND Medical Home Initiative. Other good news for the Special Population Section was that Phyllis Howard was hired as director for the Office for the Elimination of Health Disparities. Tammy will invite Phyllis to participate in a future Family Advisory Council meeting.

Department of Human Services - Tammy relayed that a news release about the program has gone out and that she and Kathy Barchenger have been in contact regarding the new waiver for medically fragile children. The new program is off to a slow start so families were encouraged to apply. A meeting of the Medical Needs Task Force is scheduled for May 20, 2008. This group continues to provide advice regarding the new waiver as implementation is initiated.

The new Buy-In program was also discussed. Tammy was unable to get an update from Medicaid Staff but believe this program is also off to a slow start. Council members suggested the following reasons why families may not be applying:

- Lack of knowledge of new programs. Families need to know that the “Children with Disabilities Program is the official name for the Buy-In program when they go to the county social service office to apply.
- Additional training of county staff may be needed regarding the new programs.
- Families may lack time to apply.
- There is a need for ongoing awareness activities.
- Families may get comments from others indicating they may not be eligible so choose not to apply.

Donene relayed Medicaid staff is doing some outreach with schools and have asked Early Intervention Experienced Parents and Family Voices staff to help identify families who may be eligible for the new waiver program. She also relayed the fact sheet on the Buy-In program is on the Family Voices website and that an article on the Buy-In program will be included in her next Family Voices newsletter.

## **CSHS Division Activities**

Medical Advisory Council Meeting Highlights – Sue reviewed highlights of the morning’s Medical Advisory Council meeting. The agenda covered provider qualifications, CSHS medical eligibility, financial eligibility/covered services/reimbursement issues, and programmatic updates. Family members will receive a copy of the Medical Advisory Council meeting minutes when they are finalized.

Utah LEND Clinic Review – Sue shared information regarding the recent clinic review conducted by Utah LEND staff. CSHS staff can provide additional information once a report is received. A handout with CSHS measures of family satisfaction that had been shared with LEND staff was reviewed. It summarized results from the clinic phone survey, cleft family interviews, and CSHS family survey. Very high satisfaction was noted with clinic services for almost all of the measures. The one area that may need improvement is the percent of families who reported receiving information regarding family support services. Donene recommended that CSHS request that contracted clinic providers utilize the Family Voices referral form. This could be recommended at the next clinic coordinator meeting.

Public Information Update – Tammy relayed that CSHS staff will be presenting at the following: Rural Health Network for Family Support Information Exchange meeting, Public Health Director of Nurses meeting, and ND Chapter of the American Academy of Pediatrics meeting.

Feedback from council members was requested on how they believe young families prefer to get needed information. Donene relayed many young parents like to get information electronically but at least one-third still prefer hardcopy. The following input on how families get information was received from council members:

- Talk to other families they know
- Talk to their doctor or get brochures at the doctors office
- Through the computer (e.g.) internet websites, e-mail, or other electronic options
- Through hospital libraries
- Talking with school staff (e.g.) school nurses, other professionals, etc.
- Through luck and hard work

ND Disability Health Project – Tammy relayed that data is now available through the ND Disability Health Project that indicates health disparities exist for people with disabilities.

Bylaw Review – Bylaws were reviewed. Tammy relayed that she'd like to strengthen the family leadership role and formalize the family co-chair at the August 2008 meeting. Bylaws will be updated to reflect the May 2008 review date.

Review of Membership Terms – The following members agreed to reappointment on the Family Advisory Council for another two-year term: Lisa, Lori, Donene, and Cheryl. Tammy will contact Laura to determine her interest in continued membership and evaluate if a tenth member would be beneficial.

Review of Syndromes Policy – Family Advisory Council members recommended proceeding with implementation of the new syndromes policy.

### **MCH Block Grant**

Review of Draft Plan Activities for FFY 2009 – The draft FFY 2009 Annual Plan was reviewed with council members. Changes from the previous year's activities were highlighted. No changes were recommended by council members. As the plan was discussed, family members provided updates on related activities and asked questions to clarify the identified work activities.

Family Participation Ranking – Tammy requested that council members turn in their family ranking sheet. Results from the combined ranking of Family Advisory Council members and CSHS staff will be reported in the FFY 2009 MCH Block Grant Application and shared with members at the August meeting.

### **Open Discussion**

Sharing of Family News – Council members and CSHS staff shared pictures of important family events.

Other Discussion – Proposed agenda or discussion items for upcoming meetings follow:

- Update on Medicaid Transportation policy
- Family leadership discussion/CSHS Family Advisory Council co-chair
- Medicaid Buy-In presentation
- Emergency Medical Services for Children – status update
- Explore idea of thumb drive as a portable medical record
- Case Scenario discussions
- Use of the family-centered care tool use in the upcoming CSHS county training event
- Information on how to understand your health care options (e.g.) new health care coverage programs available as well as your health insurance policy

Epilepsy Advocacy Association – Sue provided information on a free program on Epilepsy scheduled for May 22, 2008 in Bismarck. This information will be shared with individuals served by CSHS with seizure disorders.

### **Reimbursement Forms/Adjourn**

Reimbursement forms were completed and the meeting adjourned.

**The next meeting is scheduled Saturday, August 9, 2008 from 9:00 a.m. – 12:00 noon.**

Members opted to change from the regularly scheduled meeting date on the third Saturday in August as it conflicted with the Family Leadership Institute.