

**Children's Special Health Services  
Family Advisory Council Meeting  
Saturday, November 15, 2008**

**Welcome/Introductions/Announcements**

Tammy welcomed the following individuals to the meeting:

Present from the Family Advisory Council: Lisa Beckman, Lori Hanson (phone), Donene Feist (phone), Laura Roberts, Twyla Bohl, Cheryl Klee and Carla Peltier.

Present from the Children's Special Health Services Division: Devaiah Muccatira, Sue Burns, Alicia Phillips, and Tammy Gallup-Millner.

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

- Congratulations to Donene Feist who was one of ten exemplary Americans awarded the 2008 Robert Wood Johnson Community Health Leader Award. More information is available at the following: <http://www.communityhealthleaders.org/>
- Applications for the AMCHP Family Scholar Program were due November 7, 2008. CSHS did not submit a nomination this year as no Family Advisory Council member indicated an interest in attending; however, Donene Feist will be going as part of Family Voices.
- Various opportunities for publication, recognition, training, and family leadership development were shared since the last meeting:
  - Family Voices Leadership Institute is May 1-3, 2009 and August 7-9, 2009 in Edgeley, ND. Contact Donene Feist for more information.
  - The Catalyst Center is collecting family stories of financial hardship for use in various upcoming publications. They would like to put a face to the data. A due date for the family story collection has not been set.
  - The University of Mary Mentor Program is looking for families as trainers who live within 60 miles of Bismarck.
  - The AMCHP Board of Directors had a family representative position opening this spring with nominations due by October 31, 2008.
  - The Merle McPherson Leadership Award nomination was also due by October 31, 2008.
- For those interested in providing public comment on the new application for Developmental Disabilities Waiver Services, feedback will be accepted until December 12, 2008. Family advocates will be meeting to review and discuss the application on November 20, 2008 at 3:30 p.m. via telephone. Anyone interested in participating is encouraged to contact Donene Feist for more information. In an e-mail to Tammy, Michael Marum from the Developmental Disabilities Unit, indicated new services in the MR/DD waiver included the following: Day Habilitation, Residential Habilitation, Extended Services, Extended Home Health Care, Behavioral Consultation, Environmental Supports/Modifications, Equipment and Supplies, In-Home Supports, Parenting Support, and Transportation Costs for Financially Responsible Caregiver. For the combined Self Directed Support waiver, new services included: Extended Services, Behavioral Consultation, Environmental Supports/Modifications, and Transportation Costs for Financially Responsible Caregiver.

## **Follow-up from August Meeting**

The August 9, 2008 Family Advisory Council meeting minutes were accepted as written. Items on the Review/Recommendation form for the August 9, 2008 meeting were reviewed with council members. When discussing the Health Care Coverage Options pamphlet, Donene relayed she would be happy to add the brochure to the Family Voices website.

## **Updates**

### National Update

Tammy relayed that the 2009 Maternal and Child Health Block Grant was formally reviewed on August 14, 2008 in Utah. Some of the strengths that were recognized were knowledge of MCH needs and challenges and strong collaboration and infrastructure building efforts.

Recommendations included: 1) providing a more detailed description of public input and performance data/trends analysis, 2) continued efforts around medical home implementation, access to care, suicide prevention, transition of CYSHCN to adult care/services, and mental health and substance abuse care/services, and 3) continued promotion of parent/family and Native American involvement.

Tammy reviewed the North Dakota 'Snap Shot' of the MCH Federal-State Partnership, which contained information about MCH performance measures, block grant expenditures, family participation, other discretionary grants, and Title V contacts.

Tammy relayed she participated in an AMCHP call that focused on post-election analysis for state MCH programs. Although there is a record deficit and economic uncertainties, speakers on the call thought there would be opportunities to advance MCH issues with the change in administration. Key issues included health leaders (President Obama's cabinet as well as changes in members of Congress), the budget (impact of the federal deficit, war, and economic bailout on discretionary spending), and health reform leadership (who will champion priority health proposals). The Obama plan focuses on insuring affordable, accessible health-care to all, lowered health care costs, and public health promotion.

To educate new leaders, AMCHP is addressing a 100 day policy agenda for improving maternal and child health. Tammy asked if families were aware of any Title V champions. Donene relayed that Senator Dorgan had a child with special needs who had passed away during surgery. It was also mentioned that Senator Kennedy planned to introduce health legislation the day after the inauguration. Donene stated that Family Voices will be working on a lot of these same issues along with a movement for parent/ professional collaboration.

### State Update

Tammy routed a revised Family Advisory Council membership list around so the names and birth dates of each family's child/youth with special health-care needs could be added. She also relayed that the CSHS nurse administrator position will be filled on November 21, 2008 by Tricia Keifer and that the medical director position is expected to be filled by Dr. Joan Connell, a pediatrician in Bismarck. Although a contract was not yet signed, it is expected that Dr. Connell will start on January 1, 2009. In addition to her work with CSHS and the UND Medical School, Dr. Connell will be starting a small practice.

Tammy provided an update on the status of 2009-2011 biennial budget process including optional budget requests that were submitted to the Governor. CSHS submitted three optional

budget requests: 1) Specialty care diagnostic and treatment program, 2) Medical Home, and 3) Early Hearing Detection and Intervention. Within the Health Department, the request for the Specialty Care Program was of much higher priority than the other two. What will be included in the Governor's budget has yet to be determined.

Sue provided an update on Early Hearing Detection and Intervention sustainability meetings. Stakeholders are looking at ways to sustain the program when grant funding ends March 2011. A second meeting has been set for November 24, 2008 to continue the discussion. The Health Care Association is supporting funding for the program. Family stories will likely be needed for this agenda to move forward.

Tammy gave an update on programs within the Department of Human Services. Currently, three children are enrolled in the waiver for medically fragile children. Two additional children are in process of completing the level of need. Kathy Barchenger continues to do outreach. Tammy relayed that she contacted Curt Volesky about the Children with Disabilities Program (Medicaid Buy-In) and there are currently 12 children eligible. Curtis also relayed that effective June 1, 2008, Medicaid started continuous 12-month eligibility for children under age 19. Healthy Steps (CHIP) has increased to 150% of the federal poverty level while the Caring Program increased to 200%. Donene stated she wants ideas from Family Advisory Council members for radio contacts to promote some of these new programs. Members suggested the following: Joel Heitkamp radio show, KXMB TV noon show, Merl Pepecorn with Prairie Public radio, UND Studio 1, KNDC 1490 (Hettinger), etc.

Tammy relayed an interim legislative committee studied the Infant Development Program. The October 2008 meeting minutes included information about current funding, services by location, and retrospective rate setting, which is the current system used to pay for services. As of 10/1/2008, a total of 908 children were receiving early intervention services. It was projected that over \$10 million dollars would be expended for Infant Development during the 2007-2009 biennium.

Tammy relayed that the North Dakota Center for Persons with Disabilities at Minot State University is facilitating meetings to develop a state plan on Autism. Planning will include a needs assessment component. Families are involved in assessment and planning activities.

### **Family Leadership**

The Family leadership role on the advisory council was discussed. Twyla agreed to be co-chair for the upcoming year and will help develop the agendas. Based on Twyla's suggestion, Tammy distributed a survey for all the Family Advisory Council members to fill out. Topics of concern and interest to family members will be used to drive future meeting agendas.

Laura volunteered to be the Family Advisory Council representative at the May 2009 Medical Advisory Council meeting. Council members suggested that attendance at Medical Advisory Council meetings be rotated and that perhaps more than one Family Advisory Council member could attend. Lori and Cheryl also indicated a willingness to participate in this activity.

Members of the council have also been involved in other important leadership activities. Laura has written a book entitled *Walk by Faith not by Sight*, a devotional bible study. Donene relayed

that Evelyn did a wonderful job chairing the committee that organized a Traumatic Brain Injury Conference.

### **Systems Update**

Tammy played a brief slide show entitled *Champions for Inclusive Communities* to set the stage for discussion regarding the North Dakota Integrated Services Grant. CSHS staff are part of the grant advisory group and participate in conference call meetings which are held every two weeks. A project brochure was shared with council members. As part of the grant, a statewide stakeholder meeting will be held on December 9, 2008 in Bismarck. Laura, Twyla, and Cheryl indicated an interest in attending. Tammy will let staff at the North Dakota Centers for Persons with Disabilities know they are interested.

The first Medical Home learning collaborative is planned for late January 2009. Currently, five practices have indicated interest in participating including Dr. Shelton from Altru, Dr. Quanrud from Jamestown, Dr. Petty from Devils Lake, Dr. Carver from Minot and Dr. Tionson from MeritCare.

Donene stated that Family Voices will be hosting Topical Calls that support systems development. The call in December is on Family Centered Care and the one in January will be on Medical Home. Whoever would like to register for the call is welcome.

### **CSHS Division Activities**

Sue and Tammy briefly discussed the clinic coordinator and SSI meetings that were held September 2008. Donene from Family Voices was invited to participate to make sure the “family voice” was heard and that family support needs were being addressed.

Tammy relayed that Title V staff will soon be involved in the five year needs assessment process. A handout was shared entitled *State of Health in North Dakota – Children with Special Health Care Needs*. Devaiah provided an update on the Child and Adolescent Health Measurement Initiative (CAHMI) contract. Funding will support analysis of the 2005-2006 National CSHCN survey data for ND. Oregon State will complete a report that will hopefully be available in December.

### **Open Discussion**

No other discussion items or future meeting agenda items were brought forward by council members. Due to time constraints, the summary of findings from annual contract reports and the evaluation of the October 2008 county training event will be covered at the next meeting.

### **Reimbursement Forms/Adjourn**

Reimbursement forms were completed and the meeting adjourned.

**The next meeting will be held Saturday, February 28, 2008 from 9 a.m. to 12 noon.**