

Children's Special Health Services Family Advisory Council Meeting

**Saturday, February 28, 2009 - 9:00 p.m. to 12:00 noon CST
Comfort Suites, Meeting Room A, 929 Gateway Avenue, Bismarck, ND**

Welcome/Introductions/Announcements

Tammy welcomed the following individuals to the meeting:

Present from the Family Advisory Council: Lisa Beckman, Donene Feist, Laura Roberts, Jennifer Restemayer and Cheryl Klee (phone).

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

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

- Phyllis Howard with the Office for the Elimination of Health Disparities was invited to the meeting as a guest presenter. If unable to attend today due to travel issues, Tammy will invite her to a future meeting.
- Vocational Rehabilitation surveys were due February 13, 2009. The purpose of the surveys was to identify employment needs of individuals with disabilities and any issues encountered by providers in delivering services to individuals with disabilities.
- Tammy passed around the program from Dr. Robert M. Wentz's service and council members took a moment for reflection on his leadership role as CSHS medical director and to celebrate his life. Dr. Wentz was born September 28, 1943 and died January 3, 2009.
- Tammy relayed that a Health Issues & Disability Summit was planned for March 12, 2009 from 9:00 a.m. to 3:00 p.m. at the Student Center at Minot State University for those who might be interested in attending.
- Tricia Kiefer was introduced and warmly welcomed as a new CSHS staff member.
- Other announcements from the council membership follow:
 - Donene's son Zack signed with Valley City to play football.
 - Laura provided feedback on her experience with a new county social worker. She only had six days to complete the CSHS application for services.
 - Cheryl relayed that Shawn is doing well at UND.
 - Lisa relayed she's applying for a new job as a county eligibility tech.
 - Jennifer announced today was World Rare Disease Day.
 - Donene relayed that some of the Robert Wood Johnson money she received with her award will be used for a phone study of providers to identify where system change is most needed for new families.

Follow-up from November 2008 Meeting

- Tammy routed a membership list which was updated for any necessary changes.
- The November 2008 Family Advisory Council minutes were accepted as written. Laura relayed that her book, which is mentioned in the minutes, is expected to come out in August.

- Items on the Recommendation Summary sheet were reviewed. Donene suggested adding the Developmental Disabilities (DD) waiver to the Health Care Coverage Options pamphlet. Members who participated in the Integrated Services Grant Stakeholder meeting were acknowledged. They included Twyla, Jennifer, and Donene. Cheryl and Laura indicated a continued interest in transition. Donene relayed she would add them to the Family Advisory group for the grant.
- A list of council member's top areas of interest or concern from the survey that was completed during the last meeting was reviewed with the group. It was agreed that Tammy and Twyla try and address these areas on future meeting agendas. Priorities included the following:
 - System-related items: 1) health care coverage programs/services, 2) transition, 3) Emergency Medical Services for Children (EMSC), and an add on 4) newborn screening (ability to add conditions)
 - Condition specific items: 1) cosmetic surgery, 2) dental, 3) seizures, 4) strokes, 5) mutism
- Tammy relayed that the annual CSHS Medical Advisory Council meeting will be held May 2, 2009 from 8:30 – 12:00 noon. Laura is unable to make it this year. Tammy will check with Lori and Cheryl to see if the date works for them as both had indicated an interest in attending.

Updates

National Update

Tammy briefly reviewed the AMCHP State Profile for North Dakota and relayed it was a nice overview that highlights block grant funding, programmatic highlights, numbers served, priority needs, etc.

Tammy shared information from the 2009 Federal/State Maternal and Child Health Partnership Technical Assistance Meeting that focused heavily on the Title V 2010 Needs Assessment. In addition, speakers at the meeting addressed the 2009 budget. Increased funding may be seen in the following areas: MCH Block Grant, newborn screening, hearing screening, family to family, autism, and other earmarks (e.g., oral health, epilepsy, congenital disabilities, etc.). Although the MCH Block Grant is not directly affected, other implications of the American Recovery and Reinvestment Act were discussed that could benefit the MCH population (e.g., health care coverage, prevention, community health centers, IHS, etc.).

State Update

Council members and CSHS staff discussed health-related bills and family information and advocacy efforts during the 2009 Legislative Session. As of crossover, the Senate had made no reductions to the CSHS budget included in SB 2004, the Health Department's appropriation bill. Other related bills also have a potential impact on the Department of Health's budget (e.g., HB 1231 - Mobile Dental Care, SB 2333 - Immunizations, etc.).

Tammy relayed she is monitoring several bills that impact the children with special health care need population, including:

- HB 1012 - DHS appropriation bill (changes in eligibility for Medicaid, autism waiver, and provider rebasing)
- SB 2174 - autism task force
- HB 1478 - SCHIP eligibility

- HB 1044 - services for transition-age youth at risk, etc.
- Sue relayed that advocates were also trying to address early hearing detection and intervention funding.

Family Story – Ali Borgen Journey

Tammy talked about her meeting with Karen and Ali Borgen and referred to the flier that described their journey. The Borgen family gave permission to share this information with Family Advisory Council members because of their concern that many families find out about programs that could be helpful too late to avoid serious medical debt. Tammy identified the following ideas to improve outreach:

- Healthy Steps – work with Healthy Steps staff on a PowerPoint presentation that includes information on both programs to increase outreach potential
- Website – enhance search capability on the DoH website to better connect families to services they need, including CSHS
- Newspaper story – follow-up with DoH public information staff on a potential human interest story.
- Social services – promote the CSHS program with county and hospital social service departments at site visits
- County eligibility staff - discuss coordination and the need for referrals between eligibility and social work staff at county social service site visits
- Training - include Borgen family story as part of annual county training event
- Family Advisory Council – share information regarding Ali’s journey and solicit advice from the membership in response to the Borgen story. In addition to Tammy’s recommendations, council members suggested staff include work with the following to assure family needs are met:
 - faith-based organizations
 - insurance companies
 - childcare
 - physicians/medical education projects
 - billing offices
 - front-line staff
 - social networking options
 - nursing association
 - schools
 - charitable media options

CSHS Division Activities

Tammy relayed that revisions to the Family Handbook recommended by the advisory council were completed 1/1/2009.

Tricia gave an update on Integrated Services Grant activities. Medical Home learning collaboratives were held in February 2009 with follow-up meetings planned for April 2009. Five practice sites that have indicated interest in the learning collaboratives include Minot, Devils Lake, Jamestown, Fargo, and Grand Forks. Others will join as the project continues into 2010. Some of the goals in the learning collaborative include: 1) Development of a registry (identify which families to target), 2) use of the medical home index (a self assessment tool), 3) use of the medical home family index, and 4) development of an AIMS statement (identify areas targeted

for improvement). The medical home practice team involved in the collaborative includes a pediatrician, a nurse/social work care coordinator, and a family partner. As a practice begins its work as a medical home, Integrated Services Grant staff does a “walk through” of the clinic and meets with the practice team to offer suggestions. Family council members relayed they supported expansion of additional practices to increase medical homes for children with special health care needs.

Reimbursement Forms/Adjourn

Reimbursement forms were completed and the meeting adjourned.

The next meeting date is Saturday, May 2, 2009 from 1:00 – 4:00 p.m.

This date was scheduled to coincide with the annual Medical Advisory Council meeting. Laura and Donene relayed they could not attend the next meeting on May 2, 2009.