

Children's Special Health Services Family Advisory Council Meeting

**Saturday, March 10, 2012 - 9:00 a.m. to 12:00 noon CST
Comfort Suites, Meeting Room A, 1929 Gateway Avenue, Bismarck, ND**

Welcome/Introductions/Announcements

Tammy welcomed the following individuals to the meeting:

Present from the Family Advisory Council: Lisa Beckman, Evelyn Klimpel, Donene Feist, Cheryl Klee, Lori Hanson, Moe Schroeder, Carla Peltier and Jennifer Restemayer.

Present from Children's Special Health Services Division: Sue Burns, Melissa Evans, Brittany Getz, Kim Hruba, Devaiah Muccatira, and Tammy Gallup-Millner.

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

- Tammy introduced Brittany Getz, a new CSHS employee who started the end of January.
- Lori went to Jamaica in January and renewed her wedding vows. Her daughter Alicia will graduate in May as an LPN and may go on for a Bachelor's degree. She's a CNA and with her hearing lost, utilizes an amplified stethoscope.
- Lisa shared that her daughter Cassandra had help with dental services. There is nothing new with Kenneth. Lisa had surgery in January.
- Evelyn shared that after the flood, her family moved into a different house in Minot.
- Cheryl shared that Courtney is going to contact Voc Rehab so she can get help finding a job. She has hopes of moving into an apartment in Dickinson. Cheryl's son Shawn is a senior at UND.
- Carla shared that she has a new grandson. Her daughter attends UND. Carla also shared that she applied to go back to school with a major in educational leadership.
- Jennifer shared that she's having challenges with Allison's aides at school. Allison wrote a book on MPS which got published.
- Moe relayed that her son graduated from Early Intervention and that she took the position of Parent-to-Parent director at Family Voices. She also shared information about Project Carson, an outreach support effort for families experiencing a prenatal or at-birth diagnosis.
- Tammy shared that she will be attending her son's White Coat ceremony in March. He is half-way through med school.
- Donene shared that Zach quit football and he's going to be attending graduate school. Her daughter is going to school in Sioux Falls for social work.
- Tammy announced that the FVND Parent Leadership Institute will be held June 8-10, 2012 in Edgeley, ND. Families can apply at www.surveymonkey.com/s/656JH5Z.
- Tammy asked for a volunteer from the Family Advisory Council to be a representative at the Medical Advisory Council meeting on May 5, 2012 from 8:30 a.m. until 12:00 p.m. Cheryl, Moe, and Lori volunteered but requested that they not be responsible for a report.
- Updates or corrections were solicited to update the Family Advisory Council membership list.

- Tammy provided a recruitment update for the vacant position on the council. She had contacted Reuben Panchol through e-mail but had not heard back from him yet. Audrey Larson (Williston), Mitzi Arnold (Lincoln), and Kris Wangler (Rugby) were recommended as possible members for the vacant position.

Follow-up from November Meeting

The November 19, 2011 Family Advisory Council meeting minutes were accepted as written. Tammy passed around a hand out that she had typed up of some important notes from the guest speaker's presentation at the last meeting and asked to have it included as an addendum to the minutes. In addition to ideas included in the addendum to the November minutes, council members suggested the following:

- Provide informational tips for moms to help them better communicate with their spouse so fathers become more engaged and mothers can give up some control and be less "enabling".
- Encourage CSHS social workers to be more family-centered by interviewing the child's mom and dad rather than just the mom.
- Ask advice of other "father leaders" known to Title V. Moe said she would talk to Bob in Illinois and Rodney in Arkansas and ask if there's anything that they put in their packets for fathers as it can be hard for men to share their feelings.

The Recommendation/Review Summary was reviewed for May, August, and November 2011 meetings. Council members indicated that there is a Title V Page on the Family Voices website.

Updates

National Update

Tammy shared that the final state allocation for the FFY 2012 MCH Block Grant is unknown although grant award notifications have been received. The SSDI Block Grant was extended through January 31, 2012 but it's unclear whether additional grant funding will be forthcoming. Family Information Centers funding was not included in the President's budget but Donene is hopeful funding will be addressed through other bills. Family Voices funding ends May 2013.

Department of Health Update

Tammy shared that budget preparation for the 2013-2015 biennium will likely start in April or May. Council members were asked for input regarding possible services gaps or optional budget requests. Some of the discussion is highlighted below.

- Russell Silver Syndrome program - Four children are enrolled but only one has had claims paid through CSHS.
- Autism Spectrum Disorders - Anne Carlsen may start an autism clinic and Altru is starting one so screening/diagnostic services are growing. CSHS funding was available this biennium to support five autism clinics instead of eight as originally requested. Families recommended avoiding duplication with travel support and services of the waiver evaluation teams. They also advised that the family support piece with the autism clinic could be strengthened to include follow-through with families rather than just informational materials.
- Multidisciplinary Clinics - Diabetes Youth Outreach clinics were originally intended to assure services for more rural communities. Maysil Mallard is planning to retire and doesn't know if there will be someone to take over the administrative aspects of the program. Its possible money could be redirected to care coordination or other services. Sue shared that Sanford will be starting a craniofacial clinic and was wondering if Fargo needs two such clinics.

- Youth Transition - Tammy asked if we should concentrate more on health transition in the medical home. Moe talked about having her child take over the healthcare needs and having him more in charge. It was suggested that we have some education for parents on helping their child take over their healthcare needs.

Tammy announced *The Value of Family Leadership – Why Does It Matter* HNDECA planning meeting will be held on Tuesday, March 13, 2012 from 1:30 – 3:30 p.m. in AV Room 210. Tammy asked if any council members would be interested in attending a session with Eileen Forlenza as a guest presenter if we could get her to come to ND to speak. The council requested that an email be sent to all council members if she does come in to speak.

Department of Human Services Update

Sue shared that families are having trouble getting some things covered by Medicaid like test strips, sensors for continuous glucose monitors, and feeding tubing. CSHS is coordinating with Medicaid and gap-filling in some instances.

CSHS staff attended a recent Genetics Advisory meeting. Medicaid staff presented on codes that had been set up for specific conditions where genetic services would likely be needed that won't require prior authorization. The policy is for children from birth to age 21.

Changes in Medicaid guidelines for out-of-state services for children were discussed. Effective 3/1 2012, medically necessary, out-of-state care will be more accessible on a trial basis.

CSHS Division Program Overview and Activity Update

Family Story

Kim Hrubby, a CSHS staff member, shared her recent experience with diagnosis of her daughter's hearing loss. Although only a slight high frequency hearing loss was identified, this was an emotional experience for the whole family.

Specialty Care Diagnosis and Treatment Program

Tammy shared that CSHS is doing a lot gap filling with Medicaid and Healthy Steps. As of July 1, 2012, Early Intervention families won't be required to apply for Medicaid.

Multidisciplinary Clinics-

Kim shared that more complex family issues are cropping up in the northwestern part of the state requiring care coordination. Providers are feeling overwhelmed. It was recommended that CSHS do more outreach in the northwest part of the state through the CSHS county social service staff in Williston. Sue shared that family diversity is increasing at Fargo cleft clinics.

Metabolic Food Program

Kim shared that we are coordinating with staff in Iowa to assure ND families get linked to CSHS if babies need more diagnostic testing after newborn screening. Kim has recommended that the physician talk to the family about what testing is being done so they are better informed about what is going on. Recommendations from council members included the following:

- If a baby tests positive, connect to Project Carson.
- Share the CSHS protocol with council members for their review and recommendations.

Sue shared that 39 conditions are included in newborn screening. Conditions being considered as additions include SCID, Critical Congenital Health Disease, and EHDI.

Public Information Services

Sue passed around the *Parent Support* information packet to get feedback from the council about missing content, especially specific information for fathers. Discussion and recommendations included the following

- Add experienced parents.
- Update the *New Beginnings Guide*.
- Add *Big Tent*, a blogging site.
- Provide Lisa with more information about the Pathfinder publication.

Kim shared the *Technology* information packet, which includes a lot of IPAT information. Recommendations included the following:

- Add information on IPAD applications. Members shared that there are applications for the Ipad from the Christopher Reeve foundation that focus on mobility.
- The council suggested contacting NDCPD and Anne Carlsen Center for more ideas.
- Include the Voc Rehab brochure “Let your computer talk to you”. Evelyn Klimpel may have more information.
- Share information about the upcoming Pathfinders conference, which includes a technology track.

Tammy passed around the SPM #1 and SPM #4 fact sheets and asked for ideas or activities for the next grant cycle. The following suggestions were provided.

- Evelyn suggested strengthening partnerships with Native Americans families. A follow-up e-mail was provided with additional information.
- Moe would like to see a “Joining Forces” program where parent partners team up with department heads for support and education of families.

Tammy shared that there is high family satisfaction with CSHS public information activities. Since October 2011, 94.5% of families have been satisfied with the overall quality of information and referral services provided by CSHS (35/37).

Reimbursement Forms/Adjourn

An agenda item that was suggested for a future meeting was Early Intervention and Medicaid. Reimbursement forms were completed and the meeting adjourned.

The next meeting is scheduled for Saturday, May 5, 2012 from 1:30 to 4:30.

Note: This is a change from our usual schedule and time because of the annual Medical Advisory Council meeting.