

Children's Special Health Services Family Advisory Council Meeting

**Saturday, May 1, 2010 - 1:00 p.m. to 4:00 p.m. CST
Comfort Inn, Meeting Room F, 1030 East Interstate Avenue, Bismarck, ND**

Welcome/Introductions/Announcements

Tammy welcomed the following individuals to the meeting:

Present from the Family Advisory Council: Laura Roberts, Lisa Beckman, Evelyn Klimpel, Vicki Peterson for Donene Feist, Cheryl Klee and Lori Hanson (phone), Twyla Bohl (phone).

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

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

- Tammy handed out ND FamNet posters that provide a listing of different family support organizations that are available. Dr. Connell stated she would like pediatricians in the state to get the ND FamNet posters and that they could maybe be given out at an ND Academy of Pediatrics meeting.
- The Pathfinder Center 2010 Parent Involvement conference is scheduled for May 6-8, 2010 in Minot. Sue and Vicki indicated they were planning on attending.
- Family leadership training is scheduled August 6-8, 2010 in Edgeley. Applications are available online. Interested members can also contact Donene Feist at Family Voices.
- Tammy shared that public comments on the Children's Hospice waiver application are due by May 15, 2010. Comments can be sent to Kathy Barchenger in the Department of Human Services, Medical Services Division.
- Evelyn relayed a federal grant will support a "Think College" initiative which supports students with intellectual disabilities once they are on campus.
- Devaiah passed around the recently completed birth defect surveillance report.
- Laura shared that Cole's sinus surgery in January failed so they had to have a second procedure done. He has also been cancer free since 2002. Laura also shared that she will be giving a speech on Motherhood this coming week at Java Joy.
- Lisa is currently working on braces for her daughter and is also preparing for graduation.
- Cheryl shared that Courtney sees a neurologist. Since she has been seizure free for 8 years, she will be taken off her medication.
- Tricia announced that her family will be moving out of state. Her husband works for Bob Cat and received a job offer in Litchfield, MN.
- Vicki has been working the last four and half months with a family who has a child with Retinoblastoma. The Parent navigator team will be helping the family financially with a fundraiser.
- Lori shared that she may be moving to Grand Forks this summer. Their daughter has met with staff from Vocational Rehabilitation.

Follow-up from February 2010 Meeting

The February 20, 2010 Family Advisory Council meeting minutes were accepted as written.

Items on the Review/Recommendation Summary form for the February 20, 2010 meeting were reviewed with council members. The report "What Do ND Families Say about Health Care for CSHCN's" has been added to the CSHS web page. No action was taken on the Wiki site. Sites have been used as a personal communication tool between a provider and a family rather than as a medium to share resource

information with county staff. Tammy plans to contact Patricia Hintz with the SCHIP Program to assure there is a relationship with CSHS. The Care Coordination form needs to be updated to change the name Food Stamps on the service list to the SNAP Program. This will be addressed with future form updates. The group relayed they would like to see MCH history slides at a future meeting to celebrate 75 years of Title V. The Facebook icon has been added to the CSHS webpage. This will link anyone interested to the CSHS personal page. Exploration still needs to take place on soliciting youth input.

Updates and Other Housekeeping Items

National Update

Tammy shared that the Block Grant review will be held August 9, 2010 in Denver, Colorado. An invitation was extended to the Family Advisory Council members for either reviewing the written block grant application or to attend the review via videoconference at the Gold Seal Building 4th Floor conference room in Bismarck from 9:00 – 6:00 CST.

Tammy updated the group on Health Care Reform and some opportunities for MCH/Public Health. This fall, coverage for pre-existing conditions could be addressed. Sue Burns stated it may only pertain to existing policies so we'll need to look in more detail at the issue. Other coverage changes include young adults 26-years-old or younger who may now be able to stay on their parents insurance whether they are in school or not and foster children in that same age range who could be covered under Medicaid. Orthodontic coverage will be improved under SCHIP as will coverage for childless adults up to 133% of the federal poverty level. Some gap filling by safety net programs may still be needed even with health care reform as specifics are not yet known regarding what is included in the essential benefit plan. Funding for home visiting programs is also available. There will be a website set up by the insurance department for anyone interested in keeping up on the new information.

Housekeeping items

Tammy reviewed the Family Advisory Council Bylaws which were accepted as is. Council members still felt the reimbursement amount was fair. Membership terms were also reviewed. The Family Advisory Council members' terms that will be ending after the May meeting are Laura, Lisa, Lori and Cheryl. All responded they would like to renew for another two years. Donene was absent for this meeting and will need to be followed up with regarding her interest in participation.

CSHS Division Activities

Dr. Connell reviewed some of the following highlights from the 2010 Medical Advisory Council meeting.

- Coverage for genetic screening – Should CSHS pay only for the eligible child or also pay for family members. CSHS may only cover the child.
- Orthodontia - Orthodontia will be covered on a case-by-case basis.
- Provider qualifications – The issue discussed was who is qualified to provide services for children who need specialized care while still promoting the concept of a medical home. The Medical Advisory Council's consensus was that if a physician meets the board certification and licensure requirements and is on the CSHS list, he or she can provide care for a specific child. These same conditions and requirements would apply to Nurse Practitioners. With Physician Assistants, their supervising physician needs to meet the criteria for the CSHS list in order for CSHS to cover services. Laura was concerned that Family Practice doctors may not have needed expertise as children transition to adult providers and that an Internal Medicine physician may be better able to meet the specialty care needs within a medical home.
- ADHD – The council recommended this condition be added to the CSHS list and that medications and psychological services be covered.
- Metabolic food program expansion - Sue relayed that a Legislator is proposing CSHS cover the metabolic disorder OTC. Children's Special Health Services will form a subcommittee to look into this issue further. Dr. Carver and Dr. Martsof volunteered to sit on this committee. Laura stated that it is not fair to cover everyone without looking at income. Tricia concurred that it should be income based.

- Auditory trainer - Evelyn thought this issue was important. Vocational Rehabilitation usually covers auditory trainers for any setting.
- EHDI – Follow-up is needed, either screening in the clinic or through Right Track although some families refuse visits.
- Concerns for some of ND’s Native American population - Evelyn relayed that Indian Health Service doesn’t always tell people what programs are available (e.g., Healthy Steps). Staff may not know about the other programs or may not be open to collaboration.

MCH Block Grant:

Draft plan activities for FFY 2011 (10/1/2010 – 9/30/2011) were reviewed. The following comments were received on each state performance measure:

1. The degree to which families and American Indians participate in Title V program and policy activities.
 - Hire Native American liaison to start building relationships (e.g., Cheryl Red Feather, Sara Jumping Eagle, Harriet Skye).
 - Utilize Good Health TV provided in the waiting areas of clinics. Coordinate with SCHIP outreach.
 - Hand out ND FamNet posters.
 - Cultural Sensitivity training.
2. The percent of Medicaid enrollees receiving Early Periodic Screening, Diagnosis and Treatment (EPSDT) screening services.
 - Increase the compliance with the well child checks and prenatal visits.
 - Standardize screenings tools that are consistently used.
 - Home visiting may increase screenings.
3. The percent of children age 0 through 17 receiving health care that meets the American Academy of Pediatrics (AAP) definition of medical home.
 - Have families provide information on a flash drive for physicians to upload to their medical files so the family medical records are consolidated.
 - Provide education, training, and tools to providers to support implementation of medical homes.
 - Encourage insurance reimbursement for medical homes.
4. The percent of parents who reported that they usually or always got the specific information they needed from their child’s doctor and other health care providers during the past 12 months.
 - When families meet with social worker, review list of services on care coordination plan.
5. Increase the percent of families with children ages 0 through 2 served by an evidenced-based home visiting program.
 - Educate the nursing staff at the birthing hospital and providers at well-child checks regarding different programs and what happens after discharge. Encourage communication.
6. Decrease the percent of students who reported feeling so sad or hopeless almost every day for two weeks or more in a row that they stopped doing some usual activities during the past 12 months.
 - Increase mental health screening (e.g., Fargo pilot, annual sports physicals, etc.).
 - Need more school nurses and school counselors to provide information to families.
7. The ratio of school nurses to students in ND.
 - Need more school nurses who provide in-services and training for staff.
8. Reduce the number of students who were bullied on school property during the past 12 months.

- Have communities more involved with teens to help stop bullying.
- Assess bullying risks specifically for kids with disabilities.
- Enhance awareness through the media.
- Educate parents and students about bullying at school orientations and through school curriculum.
- Have consequences for students who do the bullying.

9. The rate of deaths to individuals ages 1 through 24 caused by intentional and unintentional injuries per 100,000 individuals.

- More awareness and screening.

10. The percent of healthy weight among adults age 18 through 44.

- More access to physical activity during the winter months.
- Make changes to the school lunch menus.
- Eat healthier at home. Time and cost are issues for families.
- Consider obesity clinic that encourages behavior change.

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 MCH Block Grant Application and shared with members at the August meeting.

Reimbursement Forms/Adjourn

Reimbursement forms were completed and the meeting adjourned.

Next meeting: Tentatively set for Saturday, August 21, 2010 from 9:00 a.m. – 12:00 noon.