

Children's Special Health Services Family Advisory Council Meeting

Saturday, May 5, 2012 - 1:30 p.m. to 4:30 p.m. 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, Evelyn Klimpel, Cheryl Klee, Lori Hanson, Carla Peltier, Jennifer Restemayer and Laura Roberts.

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

Absent: Moe Schroeder and Donene Feist.

CSHS staff announcements

- Effective May 13, 2012, Cheryl Hess will be the new Executive Director of the ND State Council on Developmental Disabilities.
- A new publication from the ND Disability Health Project is available. It's titled *Disability-Related Health Disparities among North Dakota Adults and Adolescents, 2012*.
- Tammy passed around data snapshots from the 2009/10 National Survey of Children with Special Health Care Needs (NS-CSHCN). This national survey is done every four years and is specific to CSHCN. CSHCN prevalence in ND for the 2005/06 survey was 12.2%. It increased to 13.9% in the 2009/10 survey. Trend data is available for some measures and there is national data for comparisons. Although the state surpasses the nation on several measures, limited progress has been noted at either level.

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

- Tammy passed around an article that was written by a Bismarck High School student about Laura's son Cole. Cole, who has a vision impairment, wrestles and made the honor society.
- Evelyn shared that her new house (post Minot flood) is nice.
- Jennifer shared that her daughter Allison had a book published titled *Hi, my name is Allison*. She will be doing a book signing at the library on May 15, 2012. Genzyme Corporation provided the illustrations and funded the publication. Allison's goal is to raise money for the Mucopolysaccharidosis (MPS) Society. Their family continues to have challenges with aids at school. Ashley, Jennifer's other daughter, will be playing the part of Frenchy in Grease, a Sleepy Hollow production this summer.
- Cheryl shared that Courtney will be seeing a Neurologist. They are hoping she can get off all of her medications and still remain seizure free.
- Lori shared that her daughter with a hearing impairment graduates as an LPN on May 11th. She plans to go back to school in the fall for to pursue a degree as a RN. Lori passed around photos from Jamaica.
- Lisa shared that she was enjoying her grandchild's visit.

- Carla shared that her youngest finished his first year of college. Carla will be going to University of North Dakota this fall rather than teaching. Her employer is letting her take a sabbatical so she can return to her job after she completes her schooling.
- Sue shared that her daughter will be graduating from Bismarck High School.

Follow-up from March 2012 Meeting

The following changes were recommended to the March 10, 2012 meeting minutes.

- Donene recommended Audrey Larsen and Kris Wangler and Moe recommended Mitzi from Lincoln for possible Family Advisory Council membership.
- Members were unsure who recommended Matt Belche so his name will be removed from the minutes.
- Lisa's daughter is not living in Bismarck so that statement should be removed from the minutes.

Minutes were approved as corrected. Advisory council member relayed that revised minutes do not need to be sent out to the membership but recommended they be placed on the website.

Tammy passed out the recommendation form and updated the group on the following from the March 2012 meeting:

- CSHS staff are trying to fill the vacant Family Advisory Council position after requesting contact information from various members.
- There has not been any activity yet on incorporating the additional suggestions to better involve father/father figures in MCH/CSHCN programs. Other priorities take precedence in the spring months.
- In meetings with Amanda Carlson, a Developmental Disabilities staff member, she relayed they are assessing ways to avoid duplication with autism travel support and evaluation services. Kim contacted Connie Irey for information regarding family support and follow-up provided in conjunction with the autism diagnostic clinic. Staff are assessing whether recommended changes in the process should be forwarded to the North Dakota Center for Persons with Disabilities. Jennifer shared that she attended an autism clinic as a guest. She said that limited information was given on parent support though someone introduced themselves as a family support contact. Sue talked about how we deal with parent support at our cleft clinics. It's helpful to talk to the families on site in terms people can understand. It's best not to use a cookie cutter approach rather than just handing or mailing out information. Further evaluation may be needed by CSHS staff.
- For the recommendation about providing educational materials to families on how to help their child take over their healthcare needs as part of transition, staff reviewed transition packets and suggested information was already included so no changes were made.
- There has been no activity to date for the Family Leadership training by Eileen Forlenza because training dates have not yet been established. Training maybe offered in lieu of a regular Family Advisory Council meeting.
- For the recommendation on conducting outreach in the northwest part of the state with the help of county CSHS staff, Melissa relayed she had e-mailed the Williams County social worker and the worker relayed that she has not received any calls on CSHS. Laura asked how CSHS was financially and whether CSHS was getting more money for the families moving into the state. Tammy relayed that federal funding is expected to be flat but we don't yet have final figures for ND's award. Families are moving into oil country for good paying jobs but they also have to pay a lot more for rent. Those with higher incomes would likely not meet financial eligibility for the CSHS treatment program.

- Kim included information about family support options for metabolic screening follow-up. She made a few follow-up phone calls and felt that the parents appreciated the phone call and information. Children who test positive under newborn screening are likely eligible for Early Intervention.
- Experienced parents were already included in the Parent Support packet. Since information on Family Voices is included already, a decision was made not to address Big Tent separately. Staff still need to check on the current version of the New Beginnings Guide and add recommended content for Fathers.
- Lisa was provided with the Pathfinder publication.
- Evelyn was contacted for more information on the “Let Your Computer Talk to You” brochure. The Technology packet is still in the process of being revised. Connections to the Anne Carlsen Center were recommended.
- Staff are in the process of developing the FFY 2013 plan for the MCH block grant, which includes strengthening partnerships with Native American families. Tammy forwarded information sent by Evelyn after the last meeting to staff for their review. Evelyn talked a little bit about what she sent in that e-mail. Practices vary by reservation but mistrust and myths are apparent. The amount of traditionalism a family embraces makes a difference. Evelyn also talked about home visitors. If the home visitor is a female and there is only a male home, he will not answer the door. He won’t let the female in the home because culturally men are not supposed to be alone with another female in the home. It’s not unusual in the Native American culture to involve elders in decision-making or to have someone speak on another’s behalf.
- Early Intervention and Medicaid is on the agenda for the meeting.

Updates and Other Housekeeping Items

Housekeeping items

Tammy reviewed the changes she made to the Family Advisory Council Bylaws. She took out the part referring to a co-chair and changed Officers to Leadership. Changes were approved by the membership.

Membership terms were also reviewed. Lisa, Lori, Laura, and Cheryl responded they would like to renew for another two years. Moe and Donene were absent from the meeting so will need to be contacted regarding ongoing participation. Membership contact information was also updated.

National Update

Tammy shared that the Block grant review will be held August 17, 2012 in Denver, Colorado. An invitation was extended to the Family Advisory Council members to either review the written block grant application or to attend the review via videoconference in the AV Rooms 210 and 212 of the Judicial Wing at the State Capitol in Bismarck.

State Update – 2013-2015 biennial budget preparation

Tammy relayed that division staff were preparing for the biennial budget process.

Early Intervention and Medicaid Update

Sue relayed that starting in July; families that qualify for Early Intervention won’t be required to apply for Medicaid although they will still be encouraged to do so. If the families don’t apply for Medicaid they may lose options for family support services provided through the waiver. A script is available to help program managers and early intervention staff members explain the

change. Members hoped that experienced families also had the script available. The Developmental Disabilities Division is budgeting for those families that don't apply for Medicaid. Family Advisory Council members relayed it can be overwhelming to apply and that an electronic system would be useful to link families to services. Staff shared information about the a website for the Children's Defense Fund (www.bridgetobenefits.com), which helps users determine state programs families might qualify for. The site includes a list of service programs, including CSHS that might also be helpful.

CSHS Division Activities

The 2011 Medical Advisory Council meeting minutes were made available for review by council members. Tammy relayed that 2012 minutes will be sent out once they have been finalized.

Review highlights of 2012 Medical Advisory Council meeting

Dr. Connell reviewed a few of the larger topics from the 2012 Medical Advisory Council meeting, which included the following:

- Maggie Anderson, Director of the Medical Services Division in the Department of Human Services distributed a handout on Medicaid's new out-of-state care policy, which was effective March 1, 2012. A Healthy Steps outreach campaign is in progress, targeted to reservation communities to improve children's access to health care coverage.
- For newborn screening, development of a system for Critical Congenital Heart Disease screening was discussed. Inclusion of SCID screening is pending until more is known about the pilot in Iowa. An optional budget request was recommended for early hearing detection and intervention in case future federal grants aren't available.
- CSHS is unable to expand mental health coverage because of funding limitations but will continue secondary coverage if a child has an eligible condition.
- The \$20,000 limited was exceeded twice in the last five years.
- CSHS should continue Medicaid gap filling to the extent budget allows. Some gap areas include glucose monitors/sensors, test strips, laser treatment of infant hemangioma's, and disease specific metabolic formula.
- The council made the following recommendations for orthodontic care: Reimburse similar to Medicaid with exception of handicapping malocclusion, consult with orthodontists regarding payment, develop an eligibility form for orthodontists, separate cleft vs. non cleft cases, and review qualifications for handicapping malocclusion.
- Support for the Russell Silver Syndrome program has decreased since the program was first funded. The funding is currently at \$50,000. ND law allows up to \$50,000 per child per biennium. Four children are currently enrolled but claims received have been sporadic.
- Services provided that were delegated by the specialist to nurse practitioners, physician assistants, and Family Practice physicians are going well.
- Paternal involvement has been an important focus of the CSHS Family Advisory Council during the year.
- Sue discussed that Dr. Montez, an Ear, Nose, and Throat specialist at Sanford, wants to start a craniofacial clinic. The council made the recommendation that CSHS should wait and see how Sanford's clinic develops. It would be too soon to take away an established clinic that is free.
- The contract coordinator for the Diabetes Youth Outreach Program is retiring and is unable to find a replacement. The consensus of Medical Advisory Council members is that current care is not completely adequate and that the service is still needed.

- The council made the suggestion to include established therapies in the CSHS Autism Resource Booklet and then mention the website for emerging and non-established practices.
- Information on needs assessment and health care reform was shared.

MCH Block Grant

Tammy requested that council members turn in their family ranking sheet for family participation in CSHCN programs. Results from the combined ranking of Family Advisory Council members and Children's Special Health Services staff will be reported in the MCH Block Grant Application. Members discussed that they are paid consultants to the CSHS Division.

Tammy also asked the council to write down ideas for draft state plan activities for federal fiscal year 2013 (10/1/2012 through 9/30/2013).

Other

Evelyn, Donene, and others nominated Tammy for an award, which she was honored to receive.

Reimbursement Forms/Adjourn

Reimbursement forms were completed and the meeting adjourned.

The meeting tentatively scheduled for Saturday, August 18, 2012 from 9:00 a.m. – 12:00 noon was cancelled in order to redirect resources for Family Advisory Council member attendance at the upcoming Causal Leadership Training event.