

Children's Special Health Services Family Advisory Council Meeting

**Saturday, November 17, 2012 - 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, Evelyn Klimpel, Cheryl Klee, Lori Hanson, Jennifer Restemayer, Moe Schroeder and Donene Feist

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

Absent: Joseph Liccini, Carla Peltier, and Laura Roberts

CSHS staff announcements

- Tammy informed the council of its newest member. Joseph Liccini was unable to attend today's meeting. He lives in Minot, ND and is in the Air Force. He has a daughter, Stella, who was a premie at birth and has a cleft palate and mild conductive hearing loss. Tammy asked if someone would be willing to welcome him to the council and Lori relayed she would contact him prior to the next meeting.
- Tammy shared that meeting dates for 2013 were done well in advance to assure availability of state rates for lodging. Meetings will be held on February 9th, May 4th, August 17th, and November 16th. Moe relayed she will not be able to attend the February 9th meeting because she will be at the AMCHP conference.
- Tammy announced that Moe Schroeder was one of 12 people accepted as an Association of Maternal & Child Health Programs (AMCHP) Family Scholar. CSHS staff helped fill out the application on her behalf. Among other responsibilities during the 10-month program, Moe will go to Washington, DC in February to attend the AMCHP annual conference.
- Moe shared information about the Pampered Chef Fundraiser for Hypoplastic Right Hearts. The event raises funds for the Hypoplastic Right Hearts conference to be held July 2013.
- Tammy relayed there is a Barnes and Noble Bookfair for the Pathfinder Parent Center on Friday, November 23, 2012. A portion of the sales that day will go to the Pathfinder for those who are interested in participating.
- Donene shared that Giving Hearts day is in February. She also relayed that there is a man running in the Fargo marathon who hopes to give funds to Family Voices.
- Tammy shared that FamNet has not received ongoing funding to support all of the joint projects that have been identified. FamNet members are going to meet to decide whether FamNet can be sustained.

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

- Evelyn shared that she is doing well. A man bought her flooded home in Minot and he invited her to look at the renovation. His daughter and her three kids will be living in the home.
- Lisa shared that her son is engaged. Her daughter moved to Mandan.
- Cheryl shared that Courtney may be able to get off her medicine in April. Shawn will graduate in May from the University of North Dakota Magna Cum Laude. He signed up to teach English in the Republic of Georgia, but doesn't know if he is going yet.
- Kim shared that she is expecting another child in June.
- Jennifer shared that Allison had hydrocephalus and needed a shunt placed in June. She has some functional vision back but her reading is affected. Allison raised \$1,076 for the Mucopolysaccharidosis (MPS) Society.
- Moe shared that Casey is in basketball and volleyball. Tyler had his yearly cardiac visit and everything looks good. He had to have his tonsils and adenoids out at the University of Minnesota Fairview because of anesthesia issues.
- Donene shared that she will be a grandma again in April. Zach will get his Bachelor's degree in May. He will be applying for graduate school. Her daughter switched from social work to cosmetology and is living in Sioux Falls.
- Lori shared that her youngest daughter is 19 years old, taking online classes, and living at home. Alicia is 22 years old and will be having a baby in April. She dropped out of her RN classes, but will go back after the baby is born. She is a float nurse at Altru.
- Tammy shared that her daughter got married in September and she is hoping for grandchildren at some future date.
- Devaiah's daughter is 9 years old and plays the fiddle.

Follow-up from May 2012 Meeting

There have been no changes to the Family Advisory Council membership list.

The May 5, 2012 Family Advisory Council meeting minutes were accepted as written.

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

- Revised March 2012 minutes have been posted on the CSHS website.
- There has been no activity to date on incorporating additional suggestions to better involve father/father figures in MCH/CSHCH programs, including making available informational support materials.
- There has been no activity to date on further with evaluation of autism clinic family support options but CSHS staff have participated in significant collaboration activities and monitoring of pending autism-related legislation.
- Family advisory council members were all invited to participate in the Casual Leadership training on October 18-19, 2012 in lieu of an August 2012 council meeting. Donene, Moe, Jennifer, and Evelyn participated.
- The current New Beginnings Guide has been included in the CSHS Parent Support packet.
- Anne Carlsen Center staff was contacted and recommended including a general outreach brochure that includes technology track information into the CSHS Technology information packet.

- Absent members were contacted and agreed to continuing membership in the CSHS Family Advisory Council.
- No activity to date on sending out 2012 Medical Advisory Council minutes but they will be forwarded once the minutes are finalized.
- Family Advisory Council members will be updated on the family ranking in the 2013 Block Grant application included as its been included as part of the November 2012 meeting agenda.

Updates

National Update

Tammy shared information about the status of federal funding for both the MCH and SSDI Grants. The federal fiscal year runs October through September. The funding formula for the MCH block grant has been changed slightly this year. Children in poverty are looked at differently than before, which has resulted in a decrease of about \$46,000, a 2.6% reduction for the year based on the most recent quarterly notice of grant award. There is a possibility for an 8 to 10% cut in addition to the \$46,000. Further information regarding federal funding levels won't be known until after March 2013. A 10% cut would be an additional \$175,000 reduction in Title V funding. CSHS staff is working with the accounting staff on this issue.

Tammy asked for the council's advice on what CSHS should do if funding is cut significantly. Donene suggested calling ND's Congressional delegation and telling them about the programs that families need to survive so funding isn't cut. Family Voices is using family stories to show what cuts mean to families. Cheryl asked if CSHS would cut across the board or just a few select areas. Tammy relayed that CSHS has some state mandates that would need to be a priority. Although clinics are required, state law doesn't specify the types or how many clinics need to be supported. The Diabetes Youth Outreach Program might not be reapplying for funding in the next biennium. The executive director is retiring and she can't find someone to take over so that is an area of potential savings. Council members also felt there could be duplication in evaluations for children with autism. The Diagnostic and Treatment program is also a mandate. Sue said that there is a limit of \$20,000 per child and it could be lowered. CSHS has over 100 eligible conditions on the list so the number of eligible conditions could be cut. The Metabolic food program and Russell Silver programs are state mandates. Cheryl asked if CSHS could have the family pay a portion also. Moe offered to not take the \$75.00 to come to the meeting. Lori asked about cutting back on the amount of council meetings held each year. Tammy relayed that it states in the CSHS bylaws, we have the option to hold two to four meetings a year.

SSDI got an additional notice of a grant award that brought annual funding up to \$91,000 for the year that ends November 30, 2012. Future funding levels for many federal grants are uncertain at this point in time.

Tammy shared that the MCH Block Grant review held on August 17, 2012 went very well. No requirements needed to be addressed. Staff seriously review recommendations made by all of the reviewers. Moe and Donene participated this year. The review is usually a video conference but ended up as a telephone conference because of some technological difficulties. ND received 17 out of 18 for the family participation ranking in program and policy activities in the state

CSHCN program. Tammy shared the suggested activities for the MCH Block Grant Plan that the council had come up with at the May 2012 meeting.

Department of Health Update

The governor asked state agencies for a flat 2013-2015 biennial budget. Tammy relayed that two optional budget requests were submitted by CSHS. One request was for Early Hearing Detection and Intervention (EHDI) because staff were not sure if federal funds would be available to sustain the program. The other request was for a data project because the client server application CSHS uses is very outdated. There were many optional requests submitted in the Health Department. EHDI ranked 17 out of 30 and the data project ranked 22 out of 30. Vaccine and oil impact issues were at the top of the optional budget requests within the Department. Nothing is final until the Governor's budget is released in December 2012.

The legislative messaging project will be repeated this session. Its intent is to get families stories to legislators about how state programs have helped them. Kim asked if anyone was interested in submitting a family story. Lori, Moe, Evelyn, and Cheryl each took packets. Donene shared that she would review testimony if anyone wanted to testify. Tammy relayed that written testimony can also be submitted if individuals choose not to testify in person. She will notify Family Advisory Council members when the Health Department's budget bill will be heard.

CSHS Division Program Overview and Activity Update

Administration

Autism Spectrum Disorders Update - Kim participates on the State Autism Task Force. The task force prioritized ten recommendations as requested by an interim legislative committee after a lengthy time studying autism spectrum issues in ND. Some autism-related organizations within ND didn't agree with the task force's plan and one came forth with three less costly recommendations for the interim committee to consider. One of the recommendations is an autism state registry, which will likely be the responsibility of the Health Department. CSHS is looking at other state models to come up with an estimate for how much the registry might cost, including a full-time employee. Jennifer asked if there was an age range for the registry. Kim shared that there is no age range specified. The group recommended the registry be mandated and include all individuals in ND. Another recommendation is educating professionals, which will likely be the responsibility of the Department of Public Instruction. A third recommendation is a \$30,000 voucher system for families struggling with autism that will be administered by the Department of Human Services. Moe asked if the \$30,000 was a onetime payment or a yearly payment. Kim stated that current information doesn't specify that so that will have to be clarified during the legislative session. Jennifer stated that someone from Anne Carlsen did find a state that had a voucher system. Donene stated she will have to determine her approach to testimony on this issue. There will also be an additional bill to continue the autism study and there may be another bill submitted by Senator Heckaman after the State Autism Task Force meets in January.

Kim relayed an autism booklet was updated with funding from a grant administered through the ND Center for Persons with Disabilities. They are working on a dissemination plan for the booklet so Kim asked for suggestions, which included the following:

- Family Voices requested 150

- Experienced parents (Jen requested booklets) – ND Early Intervention
- Individuals being trained through the ND Center for Persons with Disabilities autism grant
- Coordinated Treatment Center
- Anne Carlsen Center
- Have booklet available on-line
- CSHS county social service workers (received booklet at annual training event)
- CSHS Family Advisory Council members (received with November 2012 meeting packet)
- Autism groups in ND (e.g., Autism Society, Asperger's group, etc.)
- Tribal health and social work programs (e.g., Indian Health Service)
- Medical Home Care Coordinators
- Disability groups on the North Dakota university campuses

CSHS Staffing - Sue announced that she will be leaving her position in CSHS and has accepted a position in Medicaid. CSHS has experienced staffing challenges with individuals out on extended medical leave but have managed through administrative support services from Spherion and temporary staffing up to five hours per week to help with the claims workload.

Multidisciplinary Clinics

Cleft Clinic Update - Sanford Health has started a craniofacial clinic, which will be held on a quarterly basis. Sue attended the first clinic held in October, which had a small attendance. Dr. David Montes is the head of the clinic. Sue encouraged Sanford to add an audiologist to the team. There was no plastic surgeon at the October clinic. With Sanford's expansion to Bismarck, all were interested in learning more about Sioux Falls as a referral option.

Contracted Clinic Update - Tammy shared that the Asthma clinic has a long waiting list. They would like more contract funding from CSHS and are looking to expand to Dickinson. Tammy doesn't know if the resources are available to support the expansion right now. The clinic has not been able to get insurance reimbursement for the services that are provided but staff are attempting to meet with BCBS regarding the issue.

Tammy shared that the Diabetes Youth Outreach Program will likely not be applying for funding in 2013. Medical Advisory Council members still feel there is a need for diabetes outreach services in ND.

Cardiac Update – CSHS staff have conducted technical assistance calls with staff at each of the cardiac program outreach sites. Mayo has been coming to Sanford in Bismarck once a month but will now be going to St. Alexius instead. A cardiologist from Sanford in Fargo will now be providing outreach services in Bismarck.

Care Coordination

Kim shared that Ashley Howard, the care coordinator at Grand Forks Public Health, is doing well. Her caseload is steady. Kim continues to review all the care coordination plans submitted by county social service staff. The turnover in county staff is around 25%/year so technical assistance from state staff is often necessary.

Tammy shared that the annual care coordination training event was held on November 7, 2012. There were requests from medical home coordinators to attend the training so the event was opened up to more people. Tammy stated tribal health people were also invited, but there weren't any takers. A new approach was used in the training this year. Kim did an actual family interview and Moe was involved in the skit. There was also good discussion about different resources that could be used. The participants had very positive feedback about the training event overall. There was an outstanding family presentation from Karen Borgen who talked about her search for help for her child who had cancer and how her family is healing after her loss.

Public Information Services

Tammy reviewed the compiled results for the FY 2012 CSHS Health Information Satisfaction Survey. Health professionals, the internet, pamphlets/brochures, and other families are primary ways families' best obtain health-related information.

Tammy asked for input on an outreach strategy for a disability/chronic condition question on current Medicaid applications. There was a question added on the applications asking if anyone in the household has a disability. They use the question to help guide what other programs the family might be eligible for. They are currently not collecting data on other ways eligibility workers use the information. One option for follow-up is for the eligibility worker to give families information on how to apply or get in contact with the different programs often needed for children with disabilities. A second option is to have the eligibility worker talk about the handout and then introduce the family to the CSHS worker.

- Jennifer stated that giving families' information might be helpful but most families would think they weren't eligible so wouldn't act on it. She likes the idea of having them be introduced to the CSHS worker to make this more successful.
- Moe stated that she has concerns on how the question is worded and whether families understand it. They might look at it very narrowly. They have asthma and diabetes as examples so some families might look at those examples and think their child won't qualify as having a chronic condition. Moe suggested that the CSHS worker could go around and educate the other workers so they can better explain what it might mean to families.
- Tammy asked if people know right away when they apply if they qualify. Families indicated that there is a lag time.
- There is an electronic list of programs workers can access. Moe stated that if the county worker doesn't know much about the programs, then they won't talk to the families about those programs. Melissa stated that when she does an onsite new worker training, she invites the county director and eligibility workers though they don't always attend.
- Moe asked if CSHS is listed on the Early Intervention list for programs. Tammy stated she didn't know.
- Other items mentioned included the transition guide for early intervention and other electronic options (e.g., Bridge to Benefits).

Tammy shared three new resources: the *Bright Futures Family Pocket Guide*, the *Health Care Coverage Brochure*, and an *Autism Spectrum Disorder Resource Booklet*. CSHS collaborated with staff in the Family Health Division on a Bright Futures training event in November. The Health Care Coverage Brochure has been very successfully received. Jennifer requested 25 Autism booklets and 25 Health Care Coverage Brochures.

CSHCN Systems Development

ND Summit on Causal Leadership - Tammy shared that the *ND Summit on Causal Leadership – Leadership with Purpose* was held on October 18-19, 2012. Eileen Forlenza was a great speaker. The goal was to get families more involved at various levels of leadership. Eileen will be working with Family Voices for a year in follow-up to this event. Four Family Advisory Council members attended. Evelyn is involved in a committee that was formed to address cultural competence.

Newborn Screening

- Early Hearing Detection and Intervention – Wendy Thomas at the ND Center for Persons with Disabilities left and took a Special Education job at Souris Valley. Neil Sharpe is the new director.
- Critical Congenital Heart Disease (CCHD) - There will likely be a bill to add CCHD to newborn screening. This screening occurs before babies leave the hospital.
- Other conditions (e.g., SCID, MPS, Pompe's) - Becky Bailey, the Newborn Screening Program Director, attended a conference and received updates on various potential screening conditions. Iowa is in a pilot program for SCID, a condition which requires a lot of follow-up. Dr. Steve McDonough, a pediatrician in Bismarck, passed out Allison Restemayer's book on MPS at a national meeting he attended.

Reimbursement Forms/Adjourn

Reimbursement forms were completed and the meeting adjourned.

The next meeting is scheduled for Saturday, February 9, 2013 from 9:00 to 12:00.

Note: This is the second Saturday in February rather than the third Saturday.