

Children's Special Health Services Family Advisory Council Meeting

**Saturday, May 4, 2013 - 1:30 p.m. to 4:30 p.m. CST
Comfort Inn, Meeting Room E, 1030 East Interstate Avenue, Bismarck, ND**

Welcome/Introductions/Announcements

Tammy welcomed the following individuals to the meeting:

Present from the Family Advisory Council: Lisa Beckman, Evelyn Klimpel, Joseph Liccini, Cheryl Klee, Lori Hanson on by phone, Jennifer Restemayer, Moe Schroeder, and Laura Roberts.

Present from Children's Special Health Services Division: Tammie Johnson, Brittany Getz, Kim Hruby, Devaiah Muccatira, and Tammy Gallup-Millner.

Absent: Donene Feist and Carla Peltier

CSHS staff announcements:

- Tammy introduced Tammie Johnson, a new CSHS employee who started employment in the division in March.
- A webinar entitled *Sustaining and Enhancing Your Patient and Family Advisory Council* is scheduled for May 9, 2013, if folks are interested in participating.
- Donene was accepted as a fellow in the Maternal and Child Health-Public Health Leadership Institute.

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

- Evelyn shared that her son will be taking his LPN test in August. He will then start school for his RN degree. He will be turning 21 soon.
- Lori shared that her daughter Alicia's due date was last Saturday, but she has not had the baby yet.
- Cheryl shared that Shawn graduates from the University of North Dakota next Saturday. Courtney is down to one Depakote and is doing well.
- Laura shared that her family is taking a vacation to Chicago. They are also going to a national convention for Cole's genetic condition. Clay tore his shoulder and will be having surgery. Cole turned 18 and made the honor society.
- Tammy shared that her son and daughter-in-law are expecting a baby in October.
- Moe shared that the Parent Leadership Institute is June 7⁻⁹, 2013 and there are still openings. Anyone interested can email Moe or Tammy for the link.
- Jennifer shared that May 15, 2013 is MPS awareness day. She also shared that Ashley will be graduating from high school. Ashley will be the Little Mermaid in the Sleepy Hollow play and Allison is zebra fish 1. Allison has had 10 years of infusions, a total of 520 to date.

Tammy and Kim Mertz could not attend the AMCHP meeting in Washington, DC so Moe shared some highlights from the meeting. There were 850 attendees, 125 of which were family representatives. She stated that a big part of the meeting was networking with other family scholars. There were breakout sessions during the day and networking suppers at night. She attended a breakout session on medical home. She learned about telling a family story that is integrated with the MCH mission. Moe talked about family advisory meetings in Kansas. They have monthly conference calls that the families take turns leading. Moe did “Hill visits” and got to meet Senator Heidi Heitkamp and Senator Kevin Cramer’s staffers. Tammy enquired about Senator Heitkamp’s and Senator Cramer’s knowledge of Maternal Child Health being they were both new to Congress. Moe relayed the state of Maryland presented on Critical Congenital Heart Defects and how they receive funding to implement their database. All of the AMCHP sessions were recorded and are available on the AMCHP website.

Follow-up from February 2013 Meeting

The February 9, 2013 Family Advisory Council meeting minutes were accepted as written.

Tammy passed out the recommendation form and updated the group on the following from the February 2013 meeting:

- FAC recommended that brochures are available at physician offices to help inform parents about newborn screening. A newborn screening brochure is available on the Department of Health’s website and in hardcopy format. Department of Health staff conduct periodic site visits to inform health care providers about newborn screening issues.
- Encourage family responsibility in reading CSHS program-related information that is provided when they apply for diagnostic or treatment services. The CSHS Family Handbook continues to be disseminated by the state office directly to families who are eligible for the diagnostic and treatment programs. It is also available on the CSHS website. The booklet is in process of being revised. Staff encourages families to follow through with outlined responsibilities in the handbook, especially with claim-related issues. Kim shared that it is a one-stop reference for families about important CSHS programs. The Family Handbook will be brought back to the Family Advisory Council for their overview and advice.

2013 Medical Advisory Council Meeting

The 2012 Medical Advisory Council meeting minutes were made available for review by council members. Tammy relayed that 2013 minutes will be sent out once they have been finalized. Moe and Laura attended the May 2013 meeting as Family Advisory Council representatives.

Highlights of 2013 Medical Advisory Council meeting:

Dr. Connell reviewed a few of the larger topics from the 2013 Medical Advisory Council meeting, which included the following:

- For newborn screening, SCID is on the horizon. Legislation for Critical Congenital Heart Disease passed in the Legislature. The Department of Health’s role is to notify hospitals that the screening is a mandate. There is no responsibility for follow-up.
- Two or three years ago, the Medical Advisory Council decided it would be nice to cover mental health conditions, but CSHS was unable to cover them due to funding reductions/uncertainties. The council discussed who would be qualified to provide mental health services. The council decided the provider should have prescribing privileges in order to prescribe medication.
- CSHS put in an optional budget request for EDHI, but did not receive it.

- CSHS will now include transverse myelitis on the medical condition list.
- Plagiocephaly can be covered under bony deformity if it requires a helmet.
- The council decided not to cover fetal alcohol syndrome as a separate condition. Syndromes with medical involvement are currently covered.
- CSHS is still gap-filling for Medicaid.
- The council decided that INRs should be covered under treatment instead of the Cardiac Care for Children program. The treatment program has financial eligibility while the Cardiac Care for Children program does not.
- One of the key players for the craniofacial clinic in Fargo will be moving out of town.
- There was a brief overview of health care reform and the need for continued education.

Laura stated the meeting was interesting. She was not sure if she should speak at the meeting. Tammy shared that the Family Advisory members are more than welcome to participate. Jennifer would like a pediatrician in Bismarck to implement medical home. Laura talked about the social worker from the Mayo clinic who helped her a lot when Cole was diagnosed with cancer. Tammie shared that she when she worked at Medcenter One, she would coordinate the children's flight out to Mayo from Medcenter One. Mayo was doing care plans for their patients. Mayo has a good system.

Legislative Update

Tammy gave a brief overview of some of the legislative bills that CSHS has been following this legislative session.

Departmental Budgets

- **SB 2004** – Department of Health budget, which includes the Children's Special Health Services Division and a variety of other public health programs.
- **HB 1012** – Department of Human Services budget, which includes funding for various programs including those for low-income individuals and people with disabilities.

There were no significant changes to the budget that CSHS submitted as part of the Department of Health. CSHS did not receive the two optional budget requests that were submitted, one for EDHI and the other that addressed a new CSHS database. Federal funding is still uncertain for the Maternal Child Health grant and is likely to continue. Donene submitted written testimony. Moe sent written testimony to two legislators.

Autism Spectrum Disorders (ASD) - four bills were turned in to one bill.

- **HB 1038** – Comprehensive ASD bill that provides an appropriation and FTE's for the following:
 - establishment of an ASD database with mandatory reporting by qualified professionals. The Department of Health will be responsible for this and did receive an FTE for it.
 - a voucher program pilot project for individuals below 200% of the FPL from age 3 to under age 18; up to \$12,500 per year to each enrolled individual is available to help pay the costs of eligible services; bill identifies which services can and cannot be covered through the voucher (e.g., applied behavioral analysis and TEACCH are excluded while assistive technology and respite care are included).

- an expanded ASD Medicaid waiver (17 more “slots” for individuals birth through age 7).
- a Legislative Management study during the 2013-2014 interim focusing on ASD services.
- a state autism coordinator to implement a resource and service center, develop an outreach plan, conduct regional meetings and a conference, and develop a protocol for use after screenings.
- a training program for medical and behavior health providers, education staff, childcare providers, and parents.

Moe asked if the 17 slots were in addition to the 30 slots. Tammy replied yes. Jennifer asked if the child has aged out already if they would go back on the waiver. Tammy stated that she had a copy of the bill if anyone would like a copy. Some families are concerned about the reporting being mandatory for the database. Tammy felt it should be mandatory or else it would not be good quality data. Jennifer asked what information would be in the database. Tammy replied that the Department of Health will have to figure it out and will be getting a broad group together to see what should be included. Dr. Connell shared that the expansion would occur on or after January 2014. The voucher system will start on July 1, 2013. Tammy stated there were two different psychologists that had conflicting views on what was evidence-based. Laura asked if aspergers fits in with autism. Tammy stated they are looking at DSM-5 criteria. Kim shared they are doing mild to severe autism instead of aspergers. Kim stated that the fear with the new system is if a person has a diagnosis of aspergers then he/she would lose that diagnosis.

Genetics

- **SB 2131**- Relates to licensing of genetic counselors by the ND Board of Medical Examiners. Among other requirements, applicants for licensure must have a Master of Science degree from a genetic counseling training program that is accredited by the ABGC or an ABGC-approved equivalent organization and approved by the board or have a Doctoral degree from a medical genetics-training program that is accredited by the AMBG and approved by the board. We have three in North Dakota.

Screening

- **SB 2172** – Requires pulse oximetry screening for Critical Congenital Heart Defects before discharge for newborns in a hospital with a birthing center. The Department of Health is responsible for notification to medical staff and facilities regarding this new screening requirement. There was family testimony. There is no follow-up.

Health Care Coverage

- **HB 1362** – Medicaid expansion for individuals under age 65 with incomes up to 138% of the FPL. The program will be implemented either through private carriers or by utilizing the health insurance exchange. Benefits may be reduced or eliminated if federal participation decreases or is eliminated. DHS estimates 20,500 to 32,000 individuals could enroll in ND Medicaid as a result of the expansion.
- **SB 2109** – Relates to eligibility determinations for the Children’s Health Insurance Program. Use of a modified adjusted gross income (MAGI) is required by the ACA. Income limits using MAGI methodologies will be equivalent to the net income limits used previously (160% FPL).

Developmental Disabilities

- **HB 1378** - During the 2013-2014 interim, this bill requires DHS to identify the estimated cost to implement a Medicaid waiver or amend an existing Medicaid waiver, to provide coverage for children who have continued and substantial medical and support needs, but whom, at the age of three years, no longer qualify for services under the developmental disabilities waiver. DHS shall secure input from stakeholders, including families, providers, and advocates in preparing the estimate. Moe asked if they defined substantial medical need. Tammy replied no.
- **SB 2375** – Legislative management shall consider studying of home and community-based services in the state, including the need to expand the Medicaid waiver.

Mental Health

- **SB 2243**- Legislative management shall consider studying behavioral health needs of youth and adults during the 2013-14 interim.
- **SB 2306**- School districts shall provide at least two hours of professional development relating to youth suicide risk indicators, appropriate staff response, and referral sources. DPI and DoH are to collaborate in obtaining and disseminating information and training materials.

Oral Health

- **HB 1135** – Provides a \$100,000 appropriation to the Department of Health for a mobile dental care services grant to provide dental treatment, prevention, and education services to low-income and underserved children in areas of the state with limited or unavailable dental services.

Health System

- **HB 1034** – Legislative management shall study health care reform options, including implementation of the federal ACA and state alternatives for state-based health care reform. The insurance commissioner, state department of health, and department of human services are to provide status reports.
- **HB 1211** – Provides \$400,000 to the Department of Commerce to provide dollar-for-dollar matching funds to assist in the recruitment, distribution, supply, quality, and efficiency of personnel providing health services in rural areas of the state.

Child Care

- **HB 1422** – Defines group childcare and the staffing requirements for a maximum group size of children by age group and provides an appropriation to DHS for various childcare programs. \$300,000 is included to fund early childhood services specialists.
- **SB 2018** – Among other things, includes a loan guarantee for childcare facilities. \$400,000 is included for grants to support licensed early childhood services providers that care for children with disabilities or developmental delays. The grants may be used for equipment, renovation of facilities used to provide the services, and staff.
- **SB 2244** – Legislative management shall consider studying the availability of and access to childcare services in the state.

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 2014 (10/1/2013 through 9/30/2014). Lori asked if the activities were to perform those goals or to measure those goals. Tammy stated the activities are to help perform those goals. CSHS provides reports on the various measures. Lori asked how we assess these measures. Tammy relayed it varies (e.g., national surveys, data collection efforts through SSDI, etc.).

Updates and Other Housekeeping Items

Housekeeping items

Tammy reviewed the Family Advisory Council Bylaws. There were no changes to them. Tammy shared if anyone would like to take more of a leadership role in the council that it would be welcome.

Membership terms were also reviewed. Evelyn and Jennifer responded they would like to renew for another two years. Tammy stated that Carla will be contacted to see if someone else should fill her spot. Membership contact information was also updated. Cheryl stated her email is different. Moe would like her work number taken off. Lori stated that she did not get her email. There should be an underscore between the 1 and 9. Lori suggested putting the CSHS phone number, meeting one number, and division email on the membership list.

National Update

Tammy shared that the Block grant review will be held August 20 or 22, 2013 in Denver, Colorado. An invitation was extended to the Family Advisory Council members either to 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. Moe indicated her interest.

2011/2012 National Survey of Children's Health

Tammy passed around data snapshots from the 2011/2012 National Survey of Children's Health. ND is not doing well compared to the rest of the nation in developmental screening. Preventive medical and dental visits are less than the rest of the nation. Overweight and smoking issues continue. Moe asked how they did the survey. Devaiah stated the CDC does the survey.

Review of Web Content

Tammie talked briefly about the draft transition to adulthood webpage. Laura stated that the transition fair at Bismarck High School was not any help to her son Cole because he did not have a mental disability. Laura suggested having two different lists for youths with mental or physical components. Moe stated it would be good to have North Dakota related links and links for national information. Moe asked if the audience is children with special health care needs. Tammie stated it is geared towards children with special health care needs. Jennifer stated it would be nice to have the family support piece for the transition webpage. Moe suggested that Pathfinder go under education. Moe suggested adding Family Voices. Evelyn talked about a search button. Kim shared that Minot State University has job coaching. The goal of the program is to help individuals find what would be a suitable job and what interests them. The

program also works with employers to help them find an appropriate job. Evelyn asked Tammie if she talked with Gerry Teevens. Tammie stated that the Department of Public Instruction is referenced in the webpage.

Kim talked briefly about the draft family participation and satisfaction webpage. There are local, state, and national links included. Kim asked if the council would rather have the national links broken out. Jennifer replied yes. Jennifer said families really want local and state resources. Tammy stated that there is a Maternal Child Health link that is good and should still be included.

Update on CSHS Contracts

Tammy shared that 16 proposals were submitted. There were 15 continuation requests, one new proposal, and one previously funded grantee that did not reapply. CSHS awards between \$500,000 and \$550,000 per biennium. However, with funding so uncertain at the federal level, CSHS may need to prioritize which projects are funded for the upcoming biennium. Contracted services currently support multidisciplinary clinics, care coordination, medical home, and family support projects. Proposals have been reviewed independently by five separate reviewers and ranked using a point system.

Kim talked about the August meeting and asked if everyone would be able to attend. Jennifer said probably not. Moe said no. Cheryl said maybe. Laura said yes. Lisa said yes. Joe said maybe. Cancellation of the August meeting is likely due to low attendance. The next meeting is scheduled for November 16, 2013.

Reimbursement Forms/Adjourn

Reimbursement forms were completed and the meeting adjourned.