

## **Children's Special Health Services Family Advisory Council Meeting**

**Saturday, February 9, 2013 - 9:00 p.m. to 12:00 noon CST  
Comfort Suites, 929 Gateway Avenue – Bismarck, ND**

### **Welcome/Introductions/Announcements**

Tammy welcomed the following individuals to the meeting:

Present from the Family Advisory Council: Lisa Beckman, Cheryl Klee, Laura Roberts, Joseph Liccini, and Lori Hanson on by phone.

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

Absent: Donene Feist, Moe Schroeder, Evelyn Klimpel, Jennifer Restemayer, and Carla Peltier,

### **CSHS staff announcements**

- 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 May 4, 2013 (afternoon), August 17, 2013 (morning), and November 16, 2013 (morning). Lori and Lisa might not be able to attend the May meeting.
- Tammy relayed that Family Voices of ND Parent Leadership Institute will be June 7-9, 2013 in Edgeley, ND. More information is available on the Family Voices of ND website.
- Tammy asked for a volunteer from the Family Advisory Council to be a representative at the Medical Advisory Council meeting on May 4, 2013 from 8:30 a.m. until 12:00 p.m. Laura Roberts volunteered to attend the meeting. Cheryl said she might also be able to attend and would let CSHS staff know for sure.
- Tammy shared that CSHS received an enquiry from the Anne Carlsen Center about the Family Advisory Council. They are also interested in getting advice from families.
- Tammy relayed that Giving Hearts day is February 14th.

Family Advisory Council members provided the following updates or announcements:

- Cheryl shared that her daughter Courtney has not had any seizures. She is still on two medications but will decrease to one in April. She will be working at a bar and grill in Halliday. Shawn graduates from UND in May. He put in a job application at Grand Forks County Social Services.
- Laura shared Clay is in wrestling. Clay and Cole both got sick with MRSA. Cole works at the Salvation Army.
- Lori shared she has two daughters. Alicia has hearing loss and currently works as an LPN.
- Lisa shared that crime is going up in Hettinger and there are housing issues.
- Joe shared he has a two-year-old daughter named Stella who has a cleft palate. Joe is in the Air Force.

### **Follow-up from November Meeting**

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

The November 17, 2012 Family Advisory Council meeting minutes were accepted as written.

Tammy passed out the review/recommendation form and updated the group on the following from the November 2012 meeting:

- No action has been taken to date on the suggestions from the CSHS Family Advisory Council if cuts occur in MCH Block Grant funding as the final amount of federal funding will likely not be known until March 2013.
- Two family stories were submitted to the Early Childhood Comprehensive Systems program director that CSHS received for the Legislative Messaging Project. Cheryl provided one of the family stories.
- An e-mail was sent to Family Advisory Council members on 1/17/2013 regarding the Legislative hearing for the Health Department's budget bill, which was heard on 1/22/2013
- Testimony was provided on behalf of the ND Department of Health on SB 2193. Information was provided regarding mandatory reporting for the Autism Spectrum Disorder registry/database. Clarification was also addressed on who should report to assure the availability of accurate, reliable data.
- Partial dissemination has occurred for the Autism Spectrum Disorder Resource Booklet. Additional dissemination strategies have been discussed with ND Center for Persons with Disabilities (NDCPD) staff working on the Support Autism in ND grant. As there was additional money available from the SAND grant, more booklets are able to be printed. NDCPD staff have also been doing autism-related trainings throughout the state.
- No action has been taken to date on recommendations for outreach in conjunction with the disability/chronic condition questions on the current Medicaid applications.
- Autism resource booklets and Health Care Coverage brochures were brought to the February meeting for Jennifer.

## **Updates**

### National Update

Tammy presented a slideshow on Title V, which included the background and history of maternal and child health from the early 1900's to the current time. Tammy also shared information on the status of federal funding for both the MCH and SSDI Grants. There will likely be 5% cuts to 12% cuts in the MCH Block Grant. A 12% cut would likely mean a cut to services for CSHS. The President's budget is expected to be released in March or April. In May the debt ceiling will expire. Devaiah shared that the SSDI grant is usually a 5-year cycle, but was reduced to a 2-year cycle. Last year the grant was \$91,000 and this year it is \$66,000. The workload is the same, but the grant money has decreased.

### Department of Health Update

Kim shared that CSHS collaborated with staff in the Family Health Division on a Bright Futures training event in November. The training was recorded and is available online at <http://www.ndhealth.gov/brightfutures/>.

Devaiah shared that Pediatric Dental days will be held on Oct 11-12, 2013 at Prairie Knight Casino pavilion for children 0 to 18. Oral health screenings and referrals will be covered at no cost. The 12th Annual North Dakota Indian Child Welfare & Wellness Conference will be held at the Seven Seas in Mandan on February 20-22, 2013.

## **Update and Discussion on the Legislative Session**

Tammy shared that staff within the Department of Health are monitoring over 200 bills.

- SB 2004 is the Health Departments budget bill.
- CSHS is also tracking HB 1012, the Department of Human Services budget bill, which funds many supports for kids with disabilities. CSHS is also monitoring provider reimbursement levels through Medicaid as it affects CSHS. The new MMIS system is supposed to go live October 2013.
- A bill about concussion management has passed one side.
- There are four Autism bills. The interim committee received information from the Autism Task Force and other Autism groups, but the groups were not on the same page, thus several bills have been introduced this session. One bill is for a continued study. Another bill is for the Autism registry and education of professionals. Some families were concerned about confidentiality with the registry. If the registry would be voluntary, data quality would be impacted. Another autism-related bill is for a voucher system. The fourth Autism bill is a comprehensive bill that contains recommendations of the state Autism Task Force. Two state agencies asked for staff positions but not everyone agrees that FTE's are needed.
- There are bills that address genetic privacy and licensing of genetic counselors. In one, newborn screening would be an exception. Some people think that parents should sign a permission form to do the newborn screening. Cheryl mentioned having a brochure at the doctor's office to help inform parents about screening. The state currently only has three genetic counselors.
- A bill regarding child restraints failed.
- There was a bill expanding Head Start and it was turned into a study.
- There is a bill regarding expansion of the Medical Assistance Program that recently passed one side. It covers childless adults.
- Dr. Murphy tried to have a bill introduced to expand the Developmental Disabilities (DD) waiver. Many children after age 3 do not qualify for the DD waiver because they do not have an intellectual disability. A bill was introduced as a study.
- There is a bill regarding eligibility for the Children Health Insurance Program (CHIP). It would adjust eligibility based on federal changes from net to modified adjusted gross income.
- There is a bill addressing Critical Congenital Heart Disease screening. The bill passed one side. Hospitals will have to screen newborn babies but the Health Department is only required to inform hospitals about the new screening mandate. Three families testified that they did not want the bill passed as written. Some advocates wanted a follow-up system but the bill passed as written. Some people took the family's testimony to mean that service systems were failing even though the families said that their stressors eased once they were connected with CSHS, Medicaid, and Early Intervention.
- There is a bill about supporting inclusive childcare.
- There is a bill about a CHIP buy in program at 300% of poverty. The committee voted to not pass the bill.

## **CSHS Division Program Overview and Activity Update**

### Administration

Tammy relayed that there has been a third recruitment for the open position in CSHS. Nurses are in high demand and hard to get. Interviews were held in February.

### Specialty Care Diagnostic and Treatment Program

Melissa shared that families receive program information when they become eligible for CSHS. She is not sure if families are actually reading the information or if they are getting misinformation from the county. CSHS had to cover some services that are not usually covered, because a family stated that they received information from the county office that those services would be covered. She was not sure if the family misunderstood or if they were misinformed. Cheryl stated that families should read up on the program.

A second issue that has arisen is children with heart conditions who are on blood thinners so they need to be tested regularly and need INR. If the family lives far away, they could get the monitor to test at home. The problem was getting the supplies to do the testing. Many providers do not want to accept Medicaid so it is difficult to get to them to accept CSHS. CSHS cannot pay them if the providers will not enroll in Medicaid. Laura asked if CSHS could just pay the family. Tammy said this is difficult from an accounting standpoint.

### Multidisciplinary Clinics

Kim shared that CSHS will have to use an interpreter for the Fargo Cleft clinic. She also shared that CSHS has had some difficulty making sure a full complement of providers are consistently available at the cleft clinics. She indicated that the Cardiac Program is booming.

### Metabolic Food and Russell-Silver Syndrome Program

Services have been routine.

### Care Coordination

Kim shared that she is helping one PKU client who is pregnant. It is important for her to stay on her diet for the health of her baby. CSHS cannot provide metabolic food for people with OTC deficiency. It can be provided through our treatment program, but many families do not qualify financially. Kim shared that she did a site visit to assess the Grand Forks Public Health Care Coordination Program. She relayed that they are working on transferring to an electronic health records system. Kim shared that The Fundamentals of Medical Home for Children and Youth with Special Health Care Needs and Developmental Disabilities through Minot State University is now an online course where social workers and nurses can earn as many as 20 contact hours. The fee is paid by NDCPD through a grant from the Early Childhood Comprehensive Systems federal grant program. There are 25 slots available with only 12 filled so far.

### Information Resource Center

The new clinic directory is available on the CSHS website.

### State Systems Development Initiative

Devaiah shared that the current SSDI grant goals are to: 1) enhance data capacity and infrastructure for the MCH population, 2) incorporate life course perspective and metrics to inform MCH programs, policy and practice, and 3) enhance data collection, reporting capacity and the needs assessment process.

### CSHCN Systems Development

Kim shared that the Secondary Transition & Parent Involvement Conference will be held on April 11-13, 2013 at the Seven Seas in Mandan.

**Reimbursement Forms/Adjourn**

Reimbursement forms were completed and the meeting adjourned.

**The next meeting is scheduled for Saturday, May 4, 2013 from 1:30 to 4:30 p.m.**