

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

**Saturday, February 20, 2010 - 9:00 a.m. to 12:00 p.m. CT  
Comfort Inn Suites - Bismarck, ND**

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

Tammy welcomed the following individuals to the meeting:

Present from the Family Advisory Council: Laura Roberts, Lisa Beckman, Lori Hanson (phone), Evelyn Klimpel, Donene Feist (phone), Jennifer Restemayer and Twyla Bohl (phone).

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

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

- Tammy handed out new W-9 forms that need to be completed so that council members can receive timely reimbursement.
- Jennifer shared that her daughter Allison had spinal decompression surgery at the University of Minnesota on January 5, 2010.
- Evelyn relayed she has a new grandson and that her middle child graduated from college. Her youngest son Clifford is a senior in high school and has plans to become a registered nurse.
- Lisa relayed her son is now age 21 and lives in Bismarck. She recently helped her mom move into an assisted living facility. Her daughter is a senior this year and has some orthodontic needs so CSHS may be a resource.
- Laura relayed that both her boys have been successful in various sporting activities this year that that Cole has had sinus surgery. Laura will be having a book signing in Fargo on Saturday, February 20, 2010. Her book is titled *By Faith: A Family's Search for Meaning in Suffering*. She has also been asked to speak at the Women's Conference in Lier, ND on August 7, 2010.
- Lori relayed her daughter Alicia is a sophomore at UND and is in the nursing program. She has had surgery on her ears and may be checking into CSHS for help with her hearing aids. Her other daughter is 16 and is seeing a pediatric cardiologist for her cholesterol.
- Twyla relayed she has been enjoying her grandchildren and some fun cruises this year. Her family may explore services for workers with disabilities or the ticket to work program. Twyla is considering attending the Pathfinder conference this May.
- Donene has a new granddaughter. Her son Zach is in Valley City and played football this year. His last set of hearing aids was covered by Vocational Rehabilitation.
- The Family Voices of North Dakota Report – *What Do North Dakota Families Say About Health Care for Children With Special Health Care Needs* will be posted on the Family Voices web site along with the CSHS web site.

### **Follow-up from the August 2009 meeting**

The August 15, 2009 Family Advisory Council meeting minutes were accepted as written. Kelli Rice, Emergency Medical Services for Children Director, has connected with Donene regarding family stories for an upcoming Emergency Medical Services conference. Co-presenters are needed at this event. No meeting was held in November 2009.

Items on the Review/Recommendation form for the August 15, 2009 meeting were reviewed with council members. The Medical Equipment fact sheet developed by CSHS staff included generic content rather than examples of specific equipment items that might be safe to recycle. There was also a previous suggestion from the Family Advisory Council to build county staff's knowledge of state and local resources through use of a Wiki site. CSHS staff need more information about this option to see if it's an appropriate and applicable option.

### **Updates**

#### National Update

Tammy shared that the MCH Block grant was flat-funded. Tricia and Dr. John Baird will be attending the upcoming Association of Maternal and Child Health Programs conference, with travel support provided through the Integrated Services Grant. Discussions about health care reform have been quiet the last few months but may start to pick-up again soon.

#### Department of Health Update

Tammy shared that the CSHS office remodel has been completed.

#### Department of Human Services Update

Tammy updated the group on the Children with Medically Fragile Needs Waiver. A group from Medical Services and CSHS recently met. Some of the suggested changes were to reduce the points for the Level of Need determination from 40 to 30 and to build in a family component so families can share their perspective on a typical day for their child. This summary, in combination with a comment section from the child's doctor, would enable an extra 10 points to be assigned based on a team review process.

Sue updated the group on the State Children's Health Insurance Program (SCHIP). Eligibility is now at 160% of the federal poverty level based on net income. Donene stated the poverty level needs to be raised and that the buy-in eligibility option is also set too high. She relayed that families are still having problems applying at the county and that awareness of these programs needs to be enhanced. There is a new outreach coordinator at the state office, Patricia Hintz, who is the contact for the 877 *kids now* phone number. Family Advisory Council members recommended that CSHS staff provide in-service education to the new outreach coordinator to create more awareness of other disability-related programs.

### **CSHS Division Activity Update**

#### Administration

Tricia reviewed the updated care coordination form with the group. Staff relayed that families are not supposed to fill this form out on their own. Laura said she did not receive any referrals options through the county. A suggestion was made to change Food Stamps on the service list of the care coordination form to the SNAP program, which is the program's current name.

Tammy gave an overview of the Title V – Maternal & Child Health Statewide Priority Assessment Retreat with the group. The retreat was held on February 2, 2010 and included around 80 different partners who helped look at priority needs for Title V. Donene and Twyla were invited to represent the council. There were many requests made for the data which was presented at the retreat. The full PowerPoint presentation has been included on the Health Department's web site at [www.ndhealth.gov/familyhealth/](http://www.ndhealth.gov/familyhealth/). The last pages of the handout show the draft priorities which were identified. Title V staff may need to make some changes for the block grant application that will be submitted July 15, 2010. Donene shared that she received many comments that the retreat was very well organized and people felt they helped accomplish something useful. She also stated that she would like Mike Fraser's slide presentation. A suggestion was made to show slides with the history of Title V to the Family Advisory Council at a future meeting.

Tammy shared that CSHS will partner with the state of Utah in a distance learning grant if it is awarded. The grant will support didactic training around technology which states can then apply in clinical settings (e.g., connect specialists to children in rural areas via internet/webcam/conference calls, etc. to increase access to services).

#### Public Information Services

Tricia passed around new transition packets that were developed by CSHS staff. These materials are disseminated to families served by CSHS. Families were encouraged to view an 18 minute video called *Talking with your Doctor and other Health Care Professionals* which is available online at <http://hctransitions.ichp.edu/gladd/>. Laura stated she would let us know her feedback on the packets once she has reviewed them. Evelyn shared that there is a new law that states any student who has had to drop out of school due to a medical issue can still be covered under their parent's health insurance.

The H1N1 fact sheet was discussed along with the Cleft Lip and Palate Resource Booklet. The resource booklet, which is one of a series, will soon be available on the CSHS website.

Tammy briefly shared information about Bridge to Benefits. The website is designed to screen for different programs for which families may be eligible. She recently met with staff representing the Children's Defense Fund to see if CSHS could be added to the list of screened programs. Right now, CSHS is listed as a resource on the following site: [www.nd.bridgetobenefits.org](http://www.nd.bridgetobenefits.org).

Tammy relayed that the Health Information Satisfaction Survey forms that are being returned have all been positive. These forms are sent with information requests to monitor if the information going out is helpful to families.

Tricia gave an update on the Children's Special Health Services Facebook page. It is still a work in progress but the page is up and content has been updated with a link to the CSHS website, upcoming events, other helpful resources, etc. Some suggestion from advisory council members included:

- Add a place where families are able to talk with one another.
- Add the facebook icon to the CSHS website to encourage others to join.

- Solicit youth input about the CSHS facebook page as they are heavy users.

Tammy advised that the clinic directory has been completed and should be in the mail shortly. A directory was passed around for review.

### Multidisciplinary Clinics

Sue gave a brief overview of the Fargo Neurorehab clinic site visit she made. It was a follow-up clinic specifically for children with traumatic brain injury. No shows are an issue at many of the clinics and this one was no exception. Sue was able to follow a family through their clinic evaluations and provided information about traumatic brain injury to the foster mother. A positive part of the clinic was the team conference that occurred with the school.

### Systems Development Update

#### *Integrated Services Grant*

The Integrated Services Grant focuses on medical home, transition, and cultural competence/family involvement. This year more of the focus of the grant will be on sustainability. An important event included a Jumpstart Quality Improvement meeting which Donene and Tammy attended. A stakeholder meeting is planned in Bismarck on March 16, 2010. Staff are also providing input into a Care Coordination Training Curriculum, which is in the process of being developed. Different modules will help train registered nurses, social workers and others in quality care coordination. Jennifer suggested that this and other trainings be made available to the Developmental Disabilities Case managers as well.

#### *Screening*

Tammy stated that the metabolic screening program is status quo. Nationally, a recommendation is being discussed whether to add another condition to the screening panel. At the state level, there has been some legislative interest in expanding the conditions that receive support through the CSHS Metabolic Food Program. Currently just PKU and MSUD are addressed in state law. With Early Hearing Detection and Intervention, CSHS received \$50,000 this biennium to support newborn hearing screening follow-up.

#### *Family Partnership and Satisfaction*

Tammy shared that FamNet is now incorporated as a nonprofit corporation with the Secretary of State.

#### *Community-Based Service Systems*

Tricia is participating on the Governors Autism Task Force representing the Health Department. Sub groups have assigned tasks. There have been three meetings so far which have focused on collecting information and organizing for the upcoming report due in June. Donene relayed she would forward data on autism from the Family Voices survey to Tricia.

### **Family Story**

Sue shared a story about a child who screened positive for a metabolic disorder that required about 30 hours of state level care coordination. The child's pediatrician called the family about a positive metabolic screening result which had just been received from Iowa. Screening follow-up staff in Iowa told the pediatrician that the family would have to go out of state for treatment because ND didn't have anyone to treat the condition. The family subsequently went out of state

for care without prior authorization from ND Medicaid. Once CSHS staff members were made aware of the problem, extensive follow-up was done with this family to connect them to in-state treatment options. CSHS also provided the family with other resource information with a limited response back from the family.

**Reimbursement Forms/Adjourn**

Reimbursement forms were completed and the meeting adjourned.

**The next meeting is tentatively set for Saturday, May 1, 2010 from 1:00 p.m. to 4:00 p.m.**

Note: This is a change from our usual 3<sup>rd</sup> Saturday schedule and time in order to coordinate with the CSHS Medical Advisory Council meeting.