

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

**Saturday, August 15, 2009 - 9:00 a.m. to 12:00 p.m. CT  
Comfort Inn, 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, Laura Roberts, Twyla Bohl, Cheryl Klee and Jennifer Restemayer.

Present from the CSHS Division/Special Populations Section: Devaiah Muccatira, Sue Burns, Tricia Kiefer, Alicia Phillips, and Tammy Gallup-Millner.

Guests: Kelli Rice, Emergency Medical Services for Children

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

- A reminder was provided for the ND Association for the Education of Young Children (NDAEYC) Annual Conference scheduled for October 9-10, 2009 at the Seven Seas in Mandan.
- A reminder was provided for the Buddy Walk that will be held September 26, 2009 in Bismarck.
- Family Voices information, training and family support opportunities were shared. For more information, link to the Family Voices web page at: [www.fvnd.org/](http://www.fvnd.org/)
- Laura shared her book *'By Faith: A Family's Search for Meaning in Suffering'* which will soon be available in book stores.
- Jennifer relayed a Parent to Parent meeting coordinated by Family Voices and BECEP is scheduled on Monday August 17, 2009 from 5:30 p.m. to 9:30 p.m.
- Lisa shared that an Alzheimer's Memory Walk will be held on September 12, 2009 both in Dickinson and Bismarck. For more information on this event link to: [www.alz.org](http://www.alz.org).

### **Follow-up from February Meeting**

The May 2, 2009 Family Advisory Council meeting minutes were accepted as written. Items on the Review/Recommendation form for the February 28, 2009 meeting were reviewed with council members. The group suggested that in future, if staff decline potential members for the advisory council, that those families be referred to other boards. A new membership list was distributed with a "thank you" extended for the ongoing services of those who were reappointed.

### **Updates**

#### National Update

Tammy shared the changes that were made to the MCH Block Grant application based on Family Advisory Council member's advice and the results of the Family Participation Ranking. ND remained at 16 with a possible total of 18.

Tammy relayed that the MCH Block Grant review was held on August 12, 2009 in Helena, Montana. The review was very positive and funding for ND is expected without any requirements. Strengths included a wide range of MCH infrastructure building, strong collaborative partnerships, good data narrative, efforts to promote healthy lifestyles and wellness, advance planning for the 2010 needs assessment, and planned enhancements of public input processes to inform and involve MCH partners. Weaknesses included the need for more detailed description of public comment that was received about the application, a need for more detailed narrative of the state outcome measure for the ratio of the American Indian to White mortality rate due to unintentional injuries among 15 through 18 year olds, and a list of areas that remain challenging for the state (e.g., disparities, youth suicide, teen pregnancy, medical home implementation, delivery facilities for very low birth weight infants, and access to dental care for pregnant women and women of childbearing age). Recommendations included continued involvement of stakeholders and consumers in the Title V MCH Block Grant program, retention of the state outcome measure with more detailed discussion on achievement, and use of the 2010 needs assessment and MCH prioritization process to inform program planning and guide development of state performance measures so that ongoing challenges can be better addressed.

Tammy relayed that nationally lots of information is coming out regarding health care reform. The Association of Maternal & Child Health Programs has a summary of the bill versions available as does the Center for Children and Families. The Catalyst Center, which focuses on improving financing of care for children and youth with special health care needs, has developed two publications titled '*Health Care Reform and Children and Youth with Special Health Care Needs: Coverage is Not Enough*' and '*What do Children with Special Health Care Needs Require from Health Care Reform?*'. Both are available on their website at the following address: [www.catalystctr.org](http://www.catalystctr.org).

Issues that have moved closer to the top of the list in health care reform include:

- Medical Home
- Home visiting
- Public Health infrastructure
- Teen Pregnancy

Tammy relayed that a Town Hall meeting was held in Edgely, ND with Sen. Dorgan. About 150 people attended including some protestors.

#### State Update

##### **Department of Health Update:**

Tammy shared that the CSHS office will be going through an office renovation within the next few months.

A CDC hand-out was passed around addressing this year's potential flu pandemic. It included information on how to handle the flu within schools, the workforce, etc.

##### **Department of Human Services Update:**

Tammy updated the group on the Medically Fragile Waiver and Children's with Disabilities Program (Medicaid Buy-in). The Medicaid Buy-in program is still holding at 12 kids. Members relayed that some families are frustrated with the application process as they have to fill out a lot of paperwork only to find out they don't qualify. Tammy relayed she received an update from Kathy Barchenger regarding the Medically Fragile Waiver. The information Kathy has been

collecting showed there has been a lot of interest in the program; however, the number of people applying and qualifying is low.

## **CSHS Division Activities**

### Administration

Tammy reviewed the hand-out on the new policy on equipment re-use/recycling. It was relayed that this information had been included in the CSHS policies and procedures manual and the CSHS Family Handbook. A Medical Equipment fact sheet is being developed to address options on access to equipment and options for recycling. Suggestions members had included: 1) Give examples of equipment items that are safe to recycle, 2) Families could notify others about available equipment through Family Voices e-newsletter and Big Tent, and 3) Check if local DME suppliers or hospitals would store equipment so it could be recycled.

Tammy shared some background on the Title V five-year needs assessment. To gain more input, youth and family focus groups will be conducted and an electronic survey will be sent to stakeholders. Family Advisory Council members were encouraged to respond to the survey and participate in the upcoming focus groups and planning retreat.

### Public Information Services

Tammy reviewed the draft agenda for the annual county training event scheduled for October 29, 2009. Family Advisory Council members advised that state staff continue efforts to increase county staff's knowledge about state and local resources so they can provide more helpful information to families rather than focusing only on CSHS eligibility. Jennifer suggested development of a wiki site containing an updated list of resources that the county workers could utilize.

Tammy briefly reported on the availability of the *Children with Special Health-Care Needs in ND* report, the 2009 CSHS Library Catalog, and a new youth transition packet. She also relayed that a health information satisfaction survey has been created and is now included with the information sent out by CSHS.

### Systems Development Update

- Transition
  - CSHS staff are participating on the Department of Public Instruction's Health and Transition subcommittee and the Integrated Services Grant transition learning collaboratives.
  - Trish relayed she had tried to coordinate a "youth-focused" CSHS Family Advisory Council meeting to increase youth involvement in CSHS but the youth of CSHS Family Advisory Council members were not available to participate at the August meeting.
- Medical Home
  - CSHS staff are participating in the Integrated Services Grant learning collaboratives for medical home pilot practices.
  - CSHS is also involved with development of Care Coordination training modules. This is a work project through the North Dakota Center for Persons with Disabilities that was funded through a grant from the state Developmental Disabilities council. Survey responses from CSHS county service staff indicated a need for this type of training.

- CSHS has a contract with the ND Chapter of the American Academy of Pediatrics to support reimbursement for care coordination services within pilot medical home practices in the State.
- Insurance
  - The Insurance Department has involved people in CHAT (Choosing Healthplans All Together). Through this process, participants are able to provide input on essential health services. More information is available at [www.nd.gov/ndins/about/chat](http://www.nd.gov/ndins/about/chat).
  - Sue gave a brief overview of Bridges to Benefits, a program that helps family's access state-wide assistance programs. Children's Special Health Services was not included as one of the major programs but has been included as a link on the website under the "Find Other Help" section. More information about Bridges to Benefits can be found at the following: <http://nd.bridgetobenefits.org/>

### **Emergency Medical Services for Children**

Kelli Rice, Emergency Medical Services for Children (EMSC) manager, gave a PowerPoint presentation and provided attendees with a folder of information. Kelli shared the background and performance measures of the EMSC program along with information on how to be prepared in case of an emergency for a child with special health care needs.

Kelli relayed she was interested in developing an EMS protocol for children with special health care needs (CSHCN). Some of discussion highlights during the presentation follow:

- Is there a line to call for resource information regarding CSHCN? Could 911 have information available? Find out what other states are doing as options for a resource help line.
- Some families update their emergency plan annually with the help of their pediatrician. They laminate it and keep it in their child's backpack and have taken it to first responders in the area where they live.
- Person identifiable information is not used in some city systems. There are issues with people moving, HIPAA, and apartment building address vs. apartment number, etc.
- Families have concerns with their child being taken to the closest place vs. the place that knows their child best. Consider incorporating parent choice between local hospitals. Follow trauma center rules only if it's actually a trauma. Medicaid may pay only to the closest place so reimbursement may be an issue.
- If there are EMS-related concerns, families should report to the EMS Manager so she can follow-up with specific issues.
- Training is needed such as a module on CSHCN as part of Pediatric Education for Prehospital Professionals (PEPP). The state DD council was recommended as a potential funding source for this activity.
- If needed, Family Voices has an emergency form available. It is under the record keeping/care notebook link at: [http://www.fvnd.org/publications\\_2](http://www.fvnd.org/publications_2).

### **Reimbursement forms/Adjourn**

Reimbursement forms were completed and the meeting adjourned.

**The next meeting is tentatively set for Saturday, November 21, 2009 from 9:00 a.m. – 12:00 noon. (Note: This meeting was subsequently cancelled.)**

Agenda items to potentially be carried over to another meeting include:

- Review of updated care coordination form
- Screening update (metabolic and hearing)
- Family partnership and satisfaction update (FamNet update)
- Community-based service system update (Autism update, clinic coordinator meeting, SSI annual meeting, and cardiac program update)
- SCHIP outreach update