

**Children's Special Health Services
Family Advisory Council Meeting
Saturday, November 17, 2007**

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), Carla Peltier, Jennifer Restemayer, Cheryl Klee, and Twyla Bohl.

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

Present from the Family Health Division: Kimberlie Yineman

Tammy provided the following updates/announcements:

- Governor Hoeven proclaimed the week of Thanksgiving, November 18-24, 2007 as Family Week in ND. Citizens are called upon to observe this week with appropriate activities to honor the family.

Follow-up from the August meeting

The August 18, 2007 Family Advisory Council meeting minutes were accepted as written. Items listed on the Review/Recommendation form for the August 2007 meeting were reviewed with council members.

Updates

National Update

Tammy relayed that Congress had not yet passed a budget for the federal fiscal year that started October 2007 but flat funding was expected for the MCH Block Grant.

Kim, Tammy, and Devaiah attended the national Partnership meeting in October 2007. It was a good conference with a lot of focus on evidence-based best practices for the MCH population. Some of the highlights included:

- Autism – physician training that supports early identification and child development clinics for evaluation and treatment.
- Oral Health – best practice reports on oral health of individuals with special health care needs.
- Medical Home – some states have legislation that addresses medical home.
- Newborn Screening – legislation supporting screening and follow-up anticipated.
- Integrated Services – grant opportunity expected to address six CSHCN priority outcomes.
- National CSHCN Survey – 2005/2006 national survey data will be available by the end of 2007.
- Healthy Weight – big focus area across the nation.
- Bright Futures – revised edition of the child health supervision guidelines includes content on CSHCN's.

Tammy relayed that she can nominate a family advisory council member for a scholarship to attend the 2008 Association of Maternal and Child Health Programs (AMCHP) conference which will be held March 1-5, 2008 in Alexandria, Virginia. The application is due November 19, 2007. Evelyn indicated she was interested in attending and will work with Tammy to complete needed paperwork. Donene will

also be at the conference as a presenter. Jennifer relayed that Allison's picture was included in an "Expression of Hope" exhibit at Walter Reed if anyone has a chance to see it while in DC.

Tammy relayed that with ND's membership in the Association of Maternal and Child Health Programs (AMCHP), we have an opportunity to nominate a family delegate. This family liaison represents the perspective of families in Title V agency activities. Donene volunteered for this responsibility so Tammy will submit the nomination form to AMCHP.

State Update

A Department of Health update was provided regarding changes in payment for childhood vaccinations. Effective January 1, 2008, the Department of Health will no longer be able to supply vaccines for children who have health insurance. Instead, the patients' insurance companies will be billed for the cost of the vaccine. Parents are encouraged to check their insurance policies for vaccine coverage. Cost-sharing amounts will vary, depending upon the insurance plan. Certain children are still eligible to receive free vaccines through the federal Vaccines for Children program.

Tammy provided an update on activities within the Department of Human Services. An interim legislative committee is conducting an Infant Development Program study. The study was not addressed at the November 6, 2007 meeting.

Draft highlights of major themes identified in DHS stakeholder meetings that were held fall 2007 were shared with the advisory council. The following themes were identified:

- Aging demographics is already impacting service capacity
- Child welfare services are stressed in many regions
- Capacity issues exist across the system to appropriately serve children and youth transitioning out of services or into adult services
- Transportation is an issues across the state and across delivery systems
- Workforce concerns exist across the entire service delivery system from direct care workers to clinical specialists
- Capacity issues exist across the state in the mental health system
- Concerns exist about gap in substance abuse treatment system
- Support exists for technology solutions and more technical assistance
- Relationships and collaboration remain strong

Tammy provided an update regarding the new waiver for medically fragile children. Two drafts of the waiver have been informally submitted to CMS. Recommended changes have been incorporated. Kathy Barchenger has been hired as the program manager for the waiver. Meetings have been held to determine points required with level of need and to clarify roles and responsibilities between regional DD case managers and the state program manager. Draft informational materials about the program have been reviewed. A Medical Needs Task Force meeting has been scheduled for February 11, 2008. Family Advisory Council members requested an opportunity to review outreach materials to make sure they are understandable to families.

Tammy relayed that she'd talked with Curtis Volesky about the new Children with Disabilities Program, which was previously know as the buy-in eligibility option for families up to 200% FPL. It has a tentative start date of March 1, 2008. System changes are on schedule and half time staff hired. Training for county staff is planned late in January. The eligibility system at the county will help calculate which eligibility option is cheaper for the family (e.g.) medically needy with a recipient liability or buy-in with premium and no asset test. A fact sheet is planned that can be used for outreach purposes. Family Advisory Council members requested they be able to review outreach materials. Family Voices may also develop a fact sheet just for families. Council members suggested that information about new programs could be provided through CSHS county workers, Family Voices, IPAT, schools/Special Education

Units, Parent Resource Centers through Extension, Covering Kids, AAP website, Insurance Department, school nurses, and at various conferences (e.g.) Rural Health, Native American Child Welfare, Pathfinder, CEC, etc.

Review of Medical Advisory Council Recommendations and Work Plan

Sue provided a status update on recommendations received at the 2007 Medical Advisory Council meeting. The following areas were addressed: physician recertification, acquired brain injury, morbid obesity, immunodeficiency states, syndromes, mental health conditions, neuropsychological providers, covered services in conjunction with orthodontic treatment, experimental medications, transportation coverage, and council appointments. Council members relayed that both Medicaid and Tribal Health are revising transportation policies and that a medical directory would be helpful that includes all types of providers that work with the CSHCN population.

CSHS Unit Reports

Clinic coordinator and SSI annual meetings

CSHS staff relayed that the annual clinic coordinator meeting was held September 2007 with excellent attendance. Use of the Meeting One teleconference service worked well. The agenda included CSHS and Family Voices updates, discussion regarding a variety of quality assurance items as well as billings for specialty/multidisciplinary clinic services, and site reports from each of the clinic coordinators.

The annual SSI meeting was also held September 2007. Representatives from the Social Security Administration (SSA), Disability Determination Services, Medicaid, Family Voices, and CSHS were invited. The annual report was reviewed and program updates provided. Major issues discussed were anticipated work impact with SSI disability determinations with the roll-out of the new Children with Disabilities program (buy-in) and the SSA data agreement that is needed access to electronic data on children eligible for SSI.

New grant activities

Recent grant activities CSHS staff have been involved with include:

- North Dakota Disability Health Project – Administration of this five-year CDC grant is a cooperative effort between the North Dakota Center for Persons with Disabilities (NDCPD), the Center for Rural Health (CRH) and the Department of Health. Its goal is to promote health and wellness of ND citizens with disabilities and prevent or lessen effects of secondary conditions association with disabilities. CSHS staff are members of the grant advisory group which meets on a quarterly basis. Project staff are gathering information in order to develop a strategic plan. Focus group are being held at the following places:
 - Nov 20th – Devils Lake, 2-4pm and 6-8pm, Lake Region Public Library located at 423 7th St NE.
 - Nov 27th – Fargo, 2-4pm and 6-8pm, University of Mary, Butler Building, 1351 Page Drive
 - Dec 3rd – Williston, 2-4pm and 6-8pm, Williston Community Library, 1302 Davidson Drive
 - Dec 12th – Dickinson, 2-4pm and 6-8pm, Dickinson City Hall, 99 2nd St East
- Rural Health Network Family Support Grant – A three year implementation grant was submitted through the efforts of three key partners: NDCPD, CRH, and Family Voices. Goals of the grant include operation of rural health network, increased collaboration to enhance family support, and sustainability of the network. The grant will run May 2008 through April 2011 if awarded. Funding is expected to be approximately \$180,000 each year.
- Early Hearing Detection and Intervention Grant – NDCPD submitted an application for a new three year competitive grant through MCHB. If awarded, it will run April 2008 through March 2011.

- Early Childhood Comprehensive Systems Medical Home Project – A letter of intent was submitted that was needed to apply for Early Children Comprehensive Systems funding that supports medical home evaluation and web-based data collection.
- State Data Assessment Technical Assistance Mini-Grant Program – Devaiah applied for funding from AMCHP that would help pay for data linkage training and consultation.

Family Feedback on Policies and Practices - Assuring Family-Centered Care

Case scenarios were presented to council members in order for CSHS staff to get feedback regarding family-centered policies and practices. The first case involved a family that didn't want to complete the annual face-to-face visit with the county social worker at the time of their re-evaluation because "it was too far and they were too busy". CSHS requires an annual visit so the social worker and family can begin to develop a trusting, helping relationship. It assures that a trained staff member is available to help the family complete the eligibility forms correctly. The local worker gave the family several options for the visit. State staff also recommended that the transition-age youth be involved in the process. The family was informed that coverage wouldn't continue without it so they eventually complied. When asked whether the situation was handled fairly, council members made the following comments:

- It is hard to be family-centered if the family doesn't participate.
- It is disappointing the youth didn't participate as it was a lost transition opportunity. It is hard for parents to let go.
- It was good that information was laid out that coverage wouldn't continue without completion of the visit.
- CSHS staff handled the situation appropriately.
- If families want a service, they should make the time to complete necessary requirements.
- One visit per year is ok.

The second scenario involved a required screening for Medicaid as part of the CSHS eligibility determination process. This is required in CSHS policy as Title V funds are limited and used primarily for gap-filling while Medicaid is an entitlement that provides more comprehensive coverage. Despite repeated notifications, this particular family did not comply with the Medicaid screening within the 90 day time period so they had a lapse in CSHS coverage. The family contacted CSHS and requested that the program pay for an out-of-state visit. CSHS staff decided not to extend the closing date for CSHS unless the family could report extenuating circumstances that prevented them from applying for Medicaid in a timely manner. The family submitted no further information and no unusual claims were submitted. The child was eventually determined eligible for Medicaid. Comments from council members follow:

- There are natural consequences.
- Families should not expect coverage past the date of eligibility.
- The county was not responsible for the delay.
- CSHS staff did what they could and provided multiple opportunities.
- It is the same principle as not paying an insurance premium, there would be a lapse.

Oral Health for Children with Special Health Care Needs

Kimberlie Yineman, Director of the Oral Health Program in the North Dakota Department of Health, provided a report on the state of oral health in ND. She relayed that oral health is an important part of overall health. Six consultants around the state address education, prevention, and access to care. An oral health burden document is available that includes a needs assessment and plan to improve oral health. Jennifer requested a copy of the burden document. Kim relayed legislation was passed during that last session that addressed fluoride varnish and increased Medicaid reimbursement. Training will be conducted in time for the January 2008 roll-out of the varnish program. An oral health conference was recently held that focused on access to care. Some of the top policy issues included: the dental loan repayment program, oral health awareness, increased Medicaid reimbursement, expanded dental hygienist functions, and a ND

dental student rotation. ND is applying for a five-year CDC grant, which is due in December. With a good percent of dentists expected to retire in the next decade, dental workforce issues are of great concern. Kim relayed a Directory of Dental Access Programs is available at the following website address: <http://www.ndhealth.gov/oralhealth>. Once you get to the site, click on “Finding Dental Care”.

Tammy provided data on the CSHCN population and current CSHS oral health services. Some of the highlights follow:

- Chronic conditions and oral health overview
 - CSHCN’s are at increased risk for oral problems such as: 1) common oral diseases such as caries and periodontal disease, 2) serious health consequences from common oral disease due to underlying medical conditions, 3) oral consequences of medical therapies, and 4) less common oral and craniofacial problems that also affect their overall health, quality of life, and long-term outcomes.
 - CSHCN’s may be at special risk of oral disease due to delays in acquiring self-care skills, knowledge, and understanding needed to promote oral health or because of limitations in physical ability to perform personal care.
 - Barriers to care include critical dental provider workforce shortages and geographical maldistribution of providers, a lack of dental professionals trained in the care of children and special populations, and a lack of medical and other health practitioners trained in oral health promotion. Children may also lack oral health coverage, especially for complex oral and craniofacial care.
 - Oral health and medical health are connected and affect general health overall. Many systemic diseases and conditions have oral signs and symptoms (e.g.) use of medications that cause gum hyperplasia or lead to tooth decay, conditions associated with nutritional deficiencies, feeding problems, or malpositioned teeth, etc.
- Survey data
 - CSHS Family Survey - More than half of respondents indicated their child’s source of health care coverage did not pay for all of the health care services needed by their child. Of those, the most frequent response was dental/orthodontic care (32.1%) More than one-third of respondents (38.1%) mentioned their out-of-pocket health care related costs included dental or orthodontic care. Four out of five survey respondents (80%) indicated their child needed dental care, including check ups during the past 12 months
 - National Survey of CSHCN’s - Nationally, 18% of CSHCN were reported to need at least one health care service that they did not obtain in the past year. The service most commonly reported as needed but not received was dental care (8.1%).
 - National Survey of Children’s Health - Nationally, low income children and those without insurance were considerably less likely to receive preventive care. Nationally, 72.0% of children received preventive dental care in the past 12 months compared to 75.3% in ND. Nationally 68.5% of children had teeth in excellent or very good condition compared to 74.3% in ND.
 - Family Voices data - 14 encounters for information/assistance with oral health 7/06 through 6/07.
 - Oral Health in North Dakota (Burden and Plan) - 37% of individuals with a disability indicated on the 2004 BRFSS survey that they had not visited a dentist or dental hygienist within the last year, as compared to 28% of individuals with no disability.

- CSHS oral health services - A summary of selected information about CSHS coverage is included in the Oral Health Program Directory of Dental Access Programs. In FFY 2006, CSHS paid \$53,454 in claims for dental related conditions. This is 22% of all claims expenditures for the year (\$53,454 out of \$247,981 total claims). State staff have identified a need for dental care coordination for children with complex needs.

Sue facilitated a discussion with Family Advisory Council members about oral health for CSHCN's. Highlights of her presentation follow:

Challenges in Oral Health for CSHCNs

- Shortage of Pediatric dentists, many general dentists lack the knowledge and skills needed to provide care for children and adolescents with SHCN
- Many children with special health care needs lack a medical home that manages and facilitates oral health care as a part of comprehensive health care. Neglected oral health problems may exacerbate other health problems in children with special health care needs.
- Lack of a dental home (oral health professionals helping families understand what care is needed, finding a dentist who can provide necessary care, and coordinating care with specialists or other health professionals).
- Parents and caregivers need to be educated on appropriate self-care, eating healthy food and obtaining regular health care.

Opportunities to promote best practice in Oral Health for CSHCNs

- Strategies for integration of oral health in CSHS
 - Maintain an online list of dentists that are willing and able to provide services to individuals with special health care needs. The directory could list the type of patient disabilities the dentist can manage and if the dentist accepts Medicaid.
 - The Oral Health Coalition had discussed maintaining a list of providers that accepts Medicaid – we could ask them to also collect the information regarding special health care need conditions they can manage.
 - South Carolina also developed this type of directory
 - Promote oral health assessment as part of the medical home component
 - Seek input from families of CSHCN to be used in the five year needs assessment
 - Potential sources of payment should be identified to help families who, because they lack dental insurance or because of the high cost of dental procedures, cannot meet the cost of necessary treatment
 - Promote sources of free or low-cost care for families who lack dental insurance and financial resources
- Strategies for OH system improvements
 - Ask consumers to participate in the Oral Health coalition
 - Support the Ronald McDonald care mobile
 - Continuing Education in Special Care Dentistry – through continuing education requirements
 - What continuing education does ND require
 - Is there a way to provide continuing education on the Special Needs population
 - Assure that an oral health screen is included as part of an EPSDT screen

Discussion with Family Advisory Council members follows below:

- Bright Futures has dental fact sheets.
- Are consumers on the oral health coalition?
- An individual had an abscess on Friday but couldn't see the dentist until Monday so went to Canada and paid for the care
- Some families with access to IHS buy insurance. IHS only does basic care and sometimes there is a long waiting time. Individuals can't always be sent out.
- Need to book appointments well in advance (6 months).
- Pay for an appointment whether you show or not if you don't give 24 hour notice.
- Southwest ND has dentists.
- Work with Donene (Family Voices) regarding oral health information for CSHCN's.
- Fluorosis causes problems.
- Hard to buy dental insurance. It is expensive for what you get.
- Lots of gaps with the Caring Program. It offers some dental coverage.

Open Discussion

Agenda topics suggested for future Family Advisory Council meetings included an update on the buy-in eligibility option and waiver for medically fragile children and a review of the Medicaid transportation policy once it has been finalized.

Reimbursement Forms/Adjourn

Reimbursement forms were completed and the meeting adjourned.

The next meeting is tentatively set for Saturday, February 23, 2007 from 9:00 a.m. – 12:00 noon.