

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

**Comfort Suites – Meeting Room B  
Saturday – May 7, 2011  
8:30 a.m. to 12:00 noon CDT**

**Present from the Children's Special Health Services Division (CSHS):** Tamara Gallup-Millner, Division Director; Joan Connell, MD, Medical Director; Devaiah Muccatira, SSDI Program Coordinator; Sue Burns, Program Administrator; Melissa Evans, Eligibility & Claims Administrator; Denise Kirsch, Office Assistant; Diane Bruley, Administrative Assistant; and Alicia Phillips, Administrative Assistant.

**Present as Appointed Medical Advisory Council Members:** Thomas Carver, DO, Heidi Goldstein, MD, Marcus Fiechtner, MD, Jacqueline Quisno, MD, Alan Kenien, MD, DelRae Freeman for John Warford Jr., DDS, and John Martsolf, MD.

**Present from the ND Department of Human Services:** Karen Tescher, Assistant Director, Long Term Care Continuum, Medical Services Division; Erik Elkins, Assistant Director, Programs & Policy, Medical Services Division; and Gary Betting, MD, Medical Services Division Medical Consultant.

**Present as Family Advisory Council Designees:** Lori Hanson and Moe Schroeder.

**Present as Guest:** Constance Kalanek, PhD, RN, Executive Director.

**Absent:** Robert Kemp, MD, Myra Quanrud, MD, Ellen Feldman, MD, William Klava, MD, Terry Dwelle, MD, and John Baird, MD.

### **WELCOME AND INTRODUCTIONS**

Tamara Gallup-Millner gave a warm welcome and thanked the Medical Advisory Council members for their assistance during the past year. Introductions were made and the agenda reviewed.

### **OPENING REMARKS**

On behalf of the North Dakota Department of Health, Tamara Gallup-Millner extended greetings from Dr. Terry Dwelle, the State Health Officer and Dr. John Baird, the Special Populations Section Chief who had relayed their appreciation for the Council's support of the Children's Special Health Services Division over the last year.

## **CSHS OVERVIEW AND LEGISLATIVE UPDATE**

Tamara Gallup-Millner relayed that CSHS functions with eight full-time staff and the part-time services of Dr. Joan Connell, the CSHS Medical Director. Kim Hruby was unable to attend the meeting but was noted as the newest staff member in CSHS. Tammy relayed that the CSHS Division's budget for the 2009-2011 biennium, which is a combination of federal and state matching funds, was about \$2.7 million. Flat funding for the upcoming biennium is expected; however, the final budget is unknown at this time. Despite deficit reduction discussions at the federal level, final legislation was passed that rejected cuts to the state MCH block grants.

Tammy shared some programmatic highlights and reviewed reports and other handouts that were included in the meeting packet. The main focus of the Medical Advisory Council meeting is to obtain advice for the Specialty Care Diagnostic and Treatment Program. This program helps families pay for medical services for eligible children. The Legislature mandated financial eligibility for the CSHS Treatment Program at 185% of the Federal Poverty Level. That equates to a family income of \$41,352, per year, for a family of four. The only deduction allowed is annual health insurance premiums that are paid out-of-pocket.

Tammy reviewed the reports that were generated for the meeting. CSHS serves around 2,400 children per year. The top conditions identified in children served through CSHS included heart conditions, cleft lip and/or palate, asthma, diabetes, and handicapping malocclusion. Last year, ninety-one percent of the children had a source of health care coverage. The majority were privately insured while others were covered by public programs such as Medicaid or the Children's Health Insurance Program. CSHS continues to gap fill for the underinsured population; however, there has been a trend over the past few years of private insurance decreasing and public program coverage increasing in the population that CSHS is serving. With claims, the amount paid out for CSHS-covered conditions varied by type of condition.

Tammy shared that a comprehensive Maternal and Child Health Services Title V Five-Year Needs Assessment had been completed and that a link to the full document was available on the CSHS website. An executive summary of the five-year needs assessment was shared with council members. Tammy acknowledged Devaiah's contributions to this work effort. Over the next five years, CSHS will improve the health of mothers and children based, in part, on the priorities that were identified.

A legislative update was provided. The Health Department's budget was in House Bill 1004. An important consideration for the Health Department was funding linked to health care reform. One of the big items removed from the department's budget was funding for home visiting that was directed toward young children in at-risk families. Another major issue during the session was vaccine funding. Tammy relayed that CSHS had included optional budget requests to increase the eligibility level from 185% to 200% of poverty; however, that was not included in the Governor's budget. Staff submitted two additional optional budget proposals, neither of which were included in the Governor's budget. One was to support the Early Hearing Detection and Intervention Program and another was to expand asthma clinic services. The following are a few of the bills that CSHS was monitoring:

- House Bill 2268 passed, which was legislation addressing children with Autism Spectrum Disorders. This bill allowed for the development of regional Autism Spectrum Disorder Centers and consideration for an autism interim study. Funding was to come out of the Department of Human Services' budget.
- Senate Bill 2212 failed. This was a study bill addressing catastrophic diseases such as inherited metabolic disorders and the approach the state might want to take to better care for these children.
- Senate Bill 2153 failed. This bill would have expanded the metabolic food program beyond PKU and MSUD.
- Senate Bill 2067 passed. This bill expanded the newborn screening program by adding genetic disease to the metabolic newborn screening process.
- Senate Bill 2298 passed. This bill provided grants for childcare providers who care for children with special needs.
- Senate Bill 2135 and House Bill 1377 failed. These bills attempted to increase CHIP income eligibility.

### **MEDICAL SERVICES UPDATE**

Tammy welcomed Karen Tescher, Assistant Director, Long Term Care Continuum and Erik Elkins, Assistant Director, Programs & Policy from the Medical Services Division in the ND Department of Human Services (DHS). Both had graciously agreed to provide an update for council members.

Karen provided information on Senate Bill 2012, the Department of Human Services' Appropriations bill, of which a significant amount is directed to Medicaid. There was a 3% and 3% inflationary

increase for providers with the exception of physicians who were kept at the same level as before. Waiver slots were retained and services left intact. Erik provided information on the second part of Senate Bill 2012 regarding CHIP. The funding for outreach was sustained at \$650,000 and the poverty level was kept at 160%. Orthodontia was included in the CHIP funding program based on a required point system, which will take effect as of July 1, 2011. The CHIP program has been steadily increasing over the last few years with about 3,800 children currently enrolled. House Bill 1152 passed. This bill allows the Department of Human Services to pay a supplemental payment to the 36 critical access hospitals. Senate Bill 2142 passed. This bill changes “mental retardation” term to intellectual disabilities in North Dakota Century Code. House Bill 2079 passed. This bill expanded the Service Payments for the Elderly and Disabled (SPED) program, which helps provide services in the home, verses a more institutional setting.

New services that were added in 2010 were the Medicaid Hospice Waiver for Children and the Autism Waiver. Karen also provided information on the Medically Fragile Waiver. Waivers allow services that aren't in the Medicaid state plan. Karen provided informational brochures to the council but some highlights follow:

- In order for a child to be eligible for the Medically Fragile Waiver, they must qualify for Medicaid, be ages 3 to 18, be eligible to receive care in a skilled nursing home, and be living within their appointed caregiver's home. Some of the services that can be provided include transportation to out-of-state providers, respite care, case management, etc. There are currently six children enrolled with this waiver with a limit of 15 children.
- Medicaid hospice requires curative measures be stopped once the person begins to receive hospice services, whereas the Children's Hospice Waiver allows the continuation of curative measures while getting services provided through hospice (e.g., grief counseling). This waiver provides services for children who are enrolled with Medicaid but only the child's income is used to determine eligibility. It will provide health services up to the highest level of a nursing home. There are a few children currently utilizing this waiver with a limit of 30 children per year. The age limit is birth to 22 years.
- The Autism Spectrum Waiver was approved on November 1, 2010 by the Centers for Medicare and Medicaid (CMS). This waiver is provided for children from birth to age four who need at least one waiver service monthly. Each waiver year there is a limit of 30 children and currently eight are

being served. Equipment and supplies, along with in-home support and the intervention coordination, (e.g., Early Intervention specialist) are provided. Early Intervention specialists are specifically trained in Autism Spectrum Disorders. The annual maximum coverage per child is described in detail on the handout provided to the council.

Erik relayed that program integrity is being pushed within Medicare and Medicaid; therefore, several audit programs are taking place. He also shared that the MMIS system was projected to be implemented in June of 2012. He provided additional information on the following Medicaid programs:

- Medicaid's Money Follows the Person Program helps people who want to live in their own home rather than a nursing facility or an Intermediate Care Facility. Services include a housing facilitator and case manager. A marketing video has been developed.
- The PACE Program is designed to help keep the elderly in their homes instead of transferring them to a nursing facility.
- The Disease Management Program currently addresses four disease states: Asthma, Chronic Obstructive Pulmonary Disease (COPD), Congestive Heart Failure (CHF), and Diabetes. This program offers care management services, nursing services, a 24-hour hotline, face-to-face visits, telephone calls, etc.

## BUSINESS

### **Minutes**

Dr. Connell asked if there were any comments or questions regarding the 2010 minutes. Dr. Fiechtner moved to approve the 2010 meeting minutes with a spelling correction on page 3. Dr. Martsolf seconded the motion and all were in favor. The minutes were approved.

### **CSHS Medical Eligibility**

#### Autism

A Governor's task force was created that had responsibility for development of an autism spectrum disorder state plan. A CSHS staff member participates on the task force as a representative for the ND Department of Health. The task force developed the state plan and shared it with an interim legislative committee. Some of the concerns that have been identified include: 1) inadequate services, 2) scarcity

of information, and 3) the need for training of parents and professionals. North Dakota Center for Persons with Disabilities (NDCPD) is applying for a new Autism Grant to improve services for children and youth with Autism Spectrum Disorders (ASD). It is intended to address some of the needs identified in the state plan. CSHS is a partner in these efforts. Senate Bill 2268 started out as a bill mandating insurance coverage for autism therapies but evolved quite differently during the legislative process. CSHS provides funding for the Great Plains Interdisciplinary Autism Diagnostic Clinic, also known as GPIC. Clinics have been held in Jamestown and Minot two times per year.

#### Metabolic screening and medical food

Dr. Connell reviewed the expansion of metabolic food program recommendations from the last meeting:

- CSHS added Ornithine Transcarbamylase Deficiency (OTC) to the eligible condition list effective 5-1-11. Families must be financially eligibility at 185% of the Federal Poverty Level.
- CSHS researched options to address expansion of the Metabolic Food Program and a subcommittee including Tammy, Dr. Connell, Dr. Martsolf, and Dr. Carver was formed that met via conference call to provide recommendations to the Department of Health. Conditions where dietary treatment had efficacy were identified and coverage of inborn errors of metabolism by other states was researched. Iowa covers inborn errors of metabolism with funding provided by the legislature and through newborn screening fees.
- CSHS staff worked with Senator Judy Lee and Legislative Council staff on a draft bill to address the Department of Health's food program for individuals with metabolic diseases. Subsequently, SB 2153 and SB 2212 were introduced but failed to pass. Department of Health staff have initiated discussions with staff in Medical Services to promote coverage for disease-specific formulas through Medicaid.

Tammy reviewed the handout with ND newborn screening statistics. Council members discussed potential cost breaks if formula was purchased collaboratively with other states. There was also discussion about the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC) recommendation that severe combined immune deficiency (SCID) be included in newborn screening programs. This became a national standard in 2010 so ND is now exploring this addition to the newborn screening panel. Nationally, screening for hyperbilirubinemia may also be on

the horizon. CSHS contributes to the state's metabolic program by paying for care through the diagnostic and treatment program, providing formula through the metabolic food program, and funding the metabolic disorder clinics.

#### Genetic testing for cystic fibrosis for siblings with a normal sweat chloride test

At the last Medical Advisory Council meeting, it was decided not to cover genetic testing for cystic fibrosis for a sibling with a normal sweat chloride test. After the meeting, CSHS's Medical Director and Administrative staff decided to cover the testing of the sibling under the diagnostic program. The testing showed the child had two separate cystic fibrosis genes. The child will continue to be monitored to see if the cystic fibrosis advances.

#### ADD/ADHD

CSHS has not moved forward with adding ADD/ADHD due to unknown funding expectations of the Title V Block Grant.

#### Additions/Changes to the List of Medically Eligible Conditions

A handout of the CSHS Medical Condition List was provided that included conditions that were added or changed on the list effective 5-1-11. Changes included the following:

- Added Short bowel syndrome.
- Added Ornithine transcarbamylase deficiency (OTC) under Amino Acid Disorders.
- Added Inflammatory Bowel Disease, including Crohn's Disease and ulcerative colitis.
- Removed Crohn's Disease as a separate condition.

#### Proposed Changes to the List of Medically Eligible Conditions

Dr. Connell reviewed the following proposed changes to the list of medically eligible conditions:

- Change Immunodeficiency States to "Immunodeficiency States including Severe Combined Immunodeficiency (SCID)".
- Change Bony Deformities to include: "excluding acute fractures without underlying conditions".
- Add Hyperthyroidism – a draft policy was provided to the council.
- Move Hypothyroidism to an alphabetical placement on the condition list and delete "congenital" – a draft policy was provided to the council.

- The “Metabolic Disorders, limited to” heading changed to “Metabolic Disorders/Inborn Errors of Metabolism” and conditions were reorganized under the new heading – a draft policy was provided to the council. It was suggested to change the title Glutaric Acidemia/Aciduria Type 1 to Glutaric Acidemia/Aciduria to cover all types.
- It was also suggested to change the title of Muscular Dystrophy to Neuromuscular Disorders limited to those covered by the Muscular Dystrophy Association (MDA), including muscular dystrophy.
- Delete “fractures, complicated or malunited”.

Dr. Kenien motioned to accept the changes including Glutaric Acidemia/Aciduria and Muscular Dystrophy heading changes. Dr. Martsolf seconded this motion. All were in favor.

Dr. Kenien asked Dr. Connell if ND Medicaid has changed their insulin pump criteria for children with Type 1 diabetes. Dr. Connell stated she had provided comment and recommendations but to her knowledge no change had been made. Dr. Kenien made a motion that a child needs to have low C-Peptide levels but would not need to have positive antibodies to make a clinical diagnosis of Type 1 diabetes. He also asked CSHS to approach Medicaid to modify the insulin pump criteria. Dr. Martsolf seconded this motion. All were in favor.

## **Financial Eligibility, Covered Services and Reimbursement Issues**

### Covered Services and Reimbursement Issues

CSHS invited Dr. Constance Kalanek, ND Board of Nursing, to review qualifications of nurse practitioners. She stated nurse practitioners are all masters prepared, which is the minimum graduate requirement; however, they are moving toward a doctorate degree. There are four areas for advanced practice nursing: certified registered nurse anesthetist (CRNA), nurse practitioner (NP), certified nurse specialist (CNS), and nurse midwife (NM). All nurse practitioners must take a certification exam in the area of their specialty. Nurse anesthetists are required to recertify every two years and nurse practitioners are required to recertify every five years. The majority of NP’s in ND are Family NP’s although there are a few Pediatric NP’s. Currently, there are about four nurse practitioners who have an individual clinic and the remaining practitioners are within multi-professional clinics throughout the

state. During the last legislative session, the requirement for a collaborative agreement with a physician for prescriptive authority was eliminated.

Dr. Connell reviewed the policy for Primary Care/Specialty Care Reimbursement. In the following circumstances, care may be provided by a board-certified or board-eligible family practice physician, nurse practitioner, or physician assistant:

- Diagnostic Services:
  - Diagnostic evaluations relevant to CSHS eligible medical conditions will be considered for eligibility under CSHS diagnostic services. Consultation with an appropriate specialist is encouraged during diagnostic testing and required once the diagnosis has been confirmed.
- Treatment Services:
  - Preoperative care or postoperative treatment as recommended in writing by the specialist.
  - Care of an emergency nature for initial care prior to actual transfer to the specialist.
  - Short-term management can be performed by primary care providers. Long-term management must include appropriate specialist consultation and follow-up as recommended by the specialist.

Dr. Quisno motioned to accept the new Primary Care/Specialty Care Reimbursement policy with discussed changes (as written above) and Dr. Kenien seconded this motion. All were in favor.

## **Provider Qualifications**

### Recertification Report for Physicians

Melissa shared that an on-line certification resource has been implemented, which helps in checking the current certification status of physicians. Recertification letters were sent out to the providers that were not available on-line and all but about 40 have been returned.

### Financial Eligibility

Melissa gave a brief overview of children in recent years who have met the \$20,000/year payment limit. In the last five years, there have been only two children who reached the limit. There has not been anyone to reach the \$20,000 limit since 2008. CSHS coordinates with other programs when there is a child that may reach the maximum.

### Auditory trainers

Sue reviewed the draft auditory trainer policy handout. Input was sought from 15 pediatric audiologists and the parent/infant outreach coordinators at the ND School for the Deaf regarding the use of auditory trainers outside of the school setting. Only one audiologist provided a response. In her experience, one of the three children that she is seeing uses the auditory trainer at home. She stated that the children with the most severe losses were more likely to use the unit outside of the school setting. The cost of the units may make it prohibitive for families. Dr. Kenien moved to deny the coverage of the Auditory Trainer, motion seconded. All were in favor.

### Home PT/INR Monitoring

Sue reviewed the draft Home PT/INR Monitoring policy handout. A Cardiology or Hematology specialist would need to request this for a family. Blue Cross Blue Shield of ND does cover the equipment on all policies that provide home medical benefits. Medicaid does not currently cover this but is looking into it. Dr. Kenien moved to approve the Home PT/INR Monitoring system. Dr. Martsolf seconded this motion. All were in favor.

### Sound & Dry conditioning system for hearing aids

Children's Special Health Services authorized the purchase of a Sound & Dry conditioning system for hearing aids. Staff consulted with Dr. Fiechtner prior to giving approval. The system assists in drying out the hearing aids each evening when they are not in use, which can prevent water damage to the hearing aids.

### Equipment – child-specific modifications to donated equipment

At last year's Medical Advisory Council, staff discussed the policy to reuse or recycle equipment whenever possible. Dr. Klava had voiced a concern that it was difficult to have donated equipment repaired/adjusted/modified to properly fit the child when insurance or Medicaid did not purchase the equipment. This issue was discussed with Mary Helmers a staff person in ND Medicaid. She stated that Medicaid would cover equipment adjustments or part replacements as long as the child would meet Medicaid's criteria for the equipment (e.g., If the child met the need criteria for a wheelchair, ND Medicaid would authorize the necessary repairs/adjustments/modifications). The repairs/adjustments/modifications would need prior authorization.

## **Programmatic Updates**

### Family Advisory Council report

Tammy acknowledged Lori Hanson and Moe Schroeder as CSHS Family Advisory Council members and thanked them for their attendance. Lori gave a brief description of her family story and expressed her gratitude for being invited to join the meeting.

## **System of Care for Children with Special Health Care Needs (CSHCN)**

### Medical Home

The ND Integrated Services Project is ending this summer. One of the focus areas for this grant was development of medical homes for CSHCN. As part of this project, learning collaboratives were held to support development of seven medical home pilot practices in ND. Results are now available that show improvement in “medical homeness”. Included are measures for organizational capacity, chronic condition management, care coordination, community outreach, data management, and quality improvement. For more information, see the following website: [www.ndcpd.org/ndis](http://www.ndcpd.org/ndis). It was developed to help sustain the efforts that were started through the three-year grant. NDCPD is applying for a new grant to address innovative evidence-based models for improving the system of services for CSHCN’s that will focus on medical home. CSHS is a partner in this effort.

### Screening - Early Hearing Detection and Intervention (EHDI)

In 2009, 98% of all births received a hearing screening. Eleven percent of all births either missed having a hearing screen or were referred after the birth screen and 73% of these infants returned for a second screening. Of the infants that were referred for an audiological assessment, only 56% had a documented result on the web-based EHDI data system. The ND EHDI program was granted a 3-year Maternal and Child Health Bureau grant for EHDI follow-up and will receive \$300,000 each of the three years through funding that started in April 2011. The EHDI program also received supplemental dollars last summer. These funds were used to purchase new screening equipment for birthing hospitals. They also purchased screening equipment for two EPSDT/Health Tracks screening sites in Fargo and Bismarck and a pediatrician’s office. In the previous legislative session, the North Dakota Department of Health was given \$50,000 in general funds to support the EHDI program. A provider access tool was purchased for the current EHDI online data system. This tool gives providers access to all the hearing screenings and testing results that have been entered onto the system. The system is

expected to be available the end of May, 2011. The ND EHDI program has also applied for a five-year CDC data linkage grant. If it is received, it will be effective July 1, 2011.

#### Insurance – Health Benefits Counseling

CSHS is part of FamNET, a rural health network for family support. This group recently supported training on health benefits counseling. Health benefits counseling is a service that provides assistance with health care coverage that is provided by well-trained, experienced advocates. Advocacy is provided for clients without health coverage, with inadequate health coverage or for individuals who are in a dispute with their insurer. Advocacy also addresses improvements to the system of health care financing.

#### **CLOSING REMARKS/WRAP-UP**

Five physicians have terms that will be expiring this year. They include Dr. Fiechtner, Dr. Feldman, Dr. Warford, Dr. Quanrud, and Dr. Klava. Dr. Fiechtner has agreed to another term but indicated Dr. Wink would also be an option. Dr. Feldmen, Dr. Warford, Dr. Quanrud, and Dr. Klava will be contacted to determine their interest. Staff will potentially explore filling one of the vacancies with a Nurse Practitioner.

Dr. Connell closed the meeting after giving a warm thank you to the committee for all their hard work and support.