



## MEDICAL ADVISORY COUNCIL MEETING MINUTES

### CHILDREN'S SPECIAL HEALTH SERVICES

May 19, 2007

**Present from the Department of Human Services:** Maggie Anderson, Director, Medical Services Division, Department of Human Services.

**Present from Children's Special Health Services (CSHS):** Tamara Gallup-Millner, Unit Director; Robert M. Wentz, MD, Medical Director; Devaiah Muccatira, SSDI Program Coordinator; Sue Burns, Program Administrator; Leann Bayman, Eligibility & Claims Administrator; Denise Kirsch, Office Assistant; Diane Bruley, Administrative Assistant; Summer Hammond, Administrative Assistant.

**Present as Medical Advisory Council Members:** Marcus M. Fiechtner, MD, Jacob Kerbeshian, MD, Lois Freisleben Cook, MD, Ellen Ketterling, MD, Thomas Mausbach, MD, Myra Quanrud, MD, and Gary Betting, MD.

**Present as Guests:** Twyla Bohl, Family Advisory Council member and Heidi Goldstein, MD.

**Absent:** Thomas D. Carver, MD, Dennis Sommers, DDS, William Klava, MD, Terry Dwelle, MD, Bruce Levi, ND Medical Association, Joanne Luger DDS, Siriwan Kriengkrairut, MD, and Kora Dockter, CSHS.

#### **WELCOME & INTRODUCTIONS**

Tammy Gallup-Millner gave a warm welcome and thanked the Medical Advisory Council members for their assistance during the past year. Introductions were made along with an overview of the agenda.

#### **OPENING REMARKS**

Maggie Anderson, Director of the Medical Services Division, disseminated a handout with updates for the Division. Highlights are as follows:

- Medicaid Management Information System (MMIS) – The Department of Human Services is moving forward with the design, development and installation of a new MMIS, which has a scheduled implementation date of July 2009.
- SB 12 – The Department of Human Services appropriation bill included:
  - Inflationary increases for providers
  - An increase in rates for Qualified Service Providers
  - At-cost payment for Critical Access Hospitals
  - 12-month continuous eligibility for categorically needy children
  - Funds to hire a health consultant to collect cost information from providers

- Funding to sustain outreach efforts for the State Children’s Health Insurance Program
- Added income deductions for the State Children’s Health Insurance Program
- Provided additional funds to increase the fee schedule for ambulance services and chiropractic services
- Added services to the Home and Community-Based Services Waiver, including nurse management, home delivered meals, family home care for spouses, and enhanced payment for adult family foster care
- Enhanced funding for facilities that provide services to children who are medically fragile or with behavior challenges
- Provided funding for a per hour salary increase for developmental disabilities providers
- Dental Access – HB 1246 provided additional funds to enhance the dental fee schedule and HB 1293 allows practitioners, other than dentists, to apply fluoride varnish.
- Eligibility Expansion – HB 1463 expands Medicaid and SCHIP eligibility if federal changes are made when SCHIP is reauthorized and SB 2326 authorized a new Medicaid eligibility category, a Buy-In Program for children.
- New Waiver for Children – SB 2326 provides an appropriation to implement a waiver for children with extraordinary health care needs.
- Drug Use Review – HB 1422 directs the Department to review drugs in the mental health, cancer and HIV/AIDS classes during the 07-08 interim.
- Current Program/Association Discussions – Discussion areas include ambulance services, audiologists, mid-level practitioners, non-emergency transportation, and SCHIP reauthorization.
- Other Initiatives – Additional initiatives include:
  - Money Follows the Person – ND was awarded an \$8.9 million grant to assist individuals residing in nursing facilities or developmental disabilities institutions in transitioning to the community.
  - Program for All-Inclusive Care of the Elderly (PACE) – This contracted program will integrate acute and long-term care financing and services.
  - Disease Management – Pending CMS contract approval, a program will be implemented for recipients with asthma, chronic obstructive pulmonary disease, congestive heart failure, and diabetes. Local nurses will be hired to provide services with a tentative implementation date of July 1, 2007.
  - Medicaid Transformation Grant – This grant was received and addresses technology related to pharmacy claims.
  - Modernizing Medicaid – An advisory group will be addressing five or six identified areas to modernize Medicaid.

### **CSHS UNIT OVERVIEW**

Tammy Gallup-Millner provided an overview of the CSHS unit. The unit’s mission is to improve the health of children with special health care needs. It functions with eight full-time staff and the part-time services of Dr. Wentz, the CSHS Medical Director. CSHS administers MCH Title V Block Grant funds that are devoted to children with special health care needs. CSHS shares the funding from this grant with various divisions in the

Health Department. The Title V Block Grant award to North Dakota for FFY 2007 is about \$1.8 million. Of the total amount awarded through the block grant, one-third, or approximately \$610,000 is earmarked for CSHS. CSHS also receives federal funding from a State Systems Development Initiative grant, which supports MCH data related activities. The CSHS unit budget for the upcoming biennium, which is a combination of federal and state matching funds, is about \$2.5 million. Available funding is divided roughly into thirds for salaries, operating and grants lines. In a nutshell, what these budget figures mean is that with flat-funding, CSHS has the ability to tweak a few things but not to implement changes that will have a major budgetary impact.

An organizational change is planned July 1, 2007. CSHS will be transferring from the Department of Human Services to the Department of Health. Tammy acknowledged the ongoing support that had been given within the Department of Human Services and conveyed her appreciation for the good home the unit's enjoyed for many, many years. She also relayed staff were looking forward to a new beginning within the Health Department and that many efforts had already been made to welcome CSHS into the new department.

Tammy shared some programmatic highlights. Last year, CSHS served close to 2,000 children through a variety of service programs. 90% of children served had a source of health care coverage. This high percentage shows that the availability of other programs such as Healthy Steps, the Caring Program, and Medicaid is making a difference for children in our state.

In the last year, about 300 children were served in the Specialty Care Diagnostic and Treatment Program. Financial eligibility is at 185% of the federal poverty level. A few years ago, coverage was limited to \$20,000 a year. Only two or three children have met this limit. Conditions CSHS paid the most for during the year were handicapping malocclusion, diabetes mellitus, cystic fibrosis, heart conditions, cleft lip and palate, joint deformity, asthma, and seizure disorders.

In the Multidisciplinary Clinic Program, almost 1,100 kids were served. This is more than half of all the children served through CSHS. CSHS currently supports 10 different types of clinics, three of which are managed from the state office. These include the Cardiac Care for Children Program, Scoliosis clinics, and Cleft Lip and Palate clinics. CSHS funds seven other multidisciplinary clinic types which are managed by various contract entities within the state. Families have been very satisfied with the clinic services supported through CSHS.

Case management services through the Care Coordination Program continue to be provided through county social services, public health nurses, and state CSHS staff.

Twenty-two individuals were served over the last year through the Metabolic Food Program. State law requires CSHS to provide formula and low protein food for individuals with Phenylketonuria and Maple Syrup Urine Disease.

CSHS continues daily operations of an Information Resource Center. Major efforts focus on new birth families.

Currently, two children are enrolled in the Russell Silver Syndrome Program. Services include coverage of growth hormone treatment and medical food.

## **BUSINESS**

**Minutes:** Dr. Fiechtner moved to approve the 2006 meeting minutes. Dr. Cook seconded the motion and all were in favor. The minutes were approved.

### **Provider Re-Certification – CSHS Specialist List**

Some of the certification boards require physicians to re-certify. A few CSHS approved providers have not re-certified. CSHS policy requires physicians to be licensed in North Dakota and a diplomat of American or Canadian boards in their specialty, or have completed the formal educational training to take the final exam or been admitted for their final exam. Re-certification has not been a concern until lately. There are currently three CSHS participating providers that have not re-certified. Dr. Wentz and Leann Bayman drafted a letter to encourage re-certification rather than dropping the three from the list of CSHS participating providers. We will continue to monitor the situation to determine if it's a growing issue that needs to be addressed.

### **CSHS Medical Eligibility**

The council has had ongoing debates over the years on what conditions to include on the eligible list. An update on the conditions that have recently been added follows.

#### **Newborn Screening, Diagnosis and Treatment**

Tammy referred council members to a handout showing newborn screening data for various disorders. A few years ago, North Dakota expanded the number of conditions screened for at birth. Screening and short term follow-up is conducted by staff in the Health Department. When children are born with these conditions and long term follow-up is needed, services are provided by the Department of Human Services. When new babies are born, CSHS staff works with the Department of Health to make sure care is coordinated. Formula and food is mailed to individuals who have PKU and MSUD. A new collaborative effort this past year has been parent fact sheets. These resources are being developed to help families get correct and family-friendly information. CSHS staff find long term follow-up and treatment a challenge, especially as individuals move into adulthood

#### **Muscular Dystrophy**

Muscular Dystrophy (MD) was added as an eligible condition effective January 1, 2007. One child with the condition is currently eligible. CSHS sent outreach letters to the Muscular Dystrophy Association, providers, and county social workers, letting them know that CSHS recently began covering services for children with the condition.

## New Conditions

### *Acquired Brain Injury*

Dr. Wentz would like to broaden the current category of Traumatic Brain Injury, moderate to severe, to Acquired Brain Injury. Possible conditions under that category could include brain tumor, stroke, infection, toxicity, meningitis, anoxia, hydrocephalus, and traumatic injury. The council had no objections to expanding this category but recommended that CSHS define “acquired”. The council recommended coverage with the exception of perinatal types of injury such as anoxia at birth, as the focus should be on a normal brain that’s been injured.

### *Morbid Obesity*

Morbid Obesity is defined as greater than 95% BMI. If we are covering the affects of obesity, it could be cost effective to help prevent these conditions from happening. CSHS will further explore the option to support some type of clinic to help these children and their families, since services to address obesity require family involvement to be successful. With the move to the Health Department, there may be more support and resources available for this project, which requires a systems approach. CSHS could also consider coverage of secondary disabilities only.

### *Immunodeficiency States*

CSHS currently covers immunoglobulin deficiency but could broaden the category to include immunodeficiency states. Dr. Kerbeshian asked about including HIV/AIDS. CSHS likely would cover HIV/AIDS under this heading if a family applied. Dr. Fiechtner motioned to expand this category and Dr. Cook seconded. Motion passed.

### *Syndromes*

CSHS covers a few syndromes although they are not covered under that label (e.g.) MPS vs. Hurlers Syndrome. CSHS generally covers the health conditions that occur with the syndrome. For example, a child with Down syndrome could have congenital heart problems. That child would be covered because of his or her heart condition. Dr. Martsof was consulted and recommended that CSHS not cover all syndromes. He also recommended that CSHS consider the following: 1) If a child had a medically eligible condition, then the child should be potentially eligible for any syndrome related to that condition, and 2) Cover syndromes related to particular body systems (e.g.) cardiac.

CSHS also called program staff in South Dakota and Wyoming to determine their coverage guidelines. Wyoming responded that they cover syndromes if they are inherited. Nurses review medical reports and complete necessary research for conditions that are not included on their condition list and then make a determination of eligibility. Tammy called South Dakota and their coverage includes “multiple anomaly syndromes, genetic conditions, and chromosomal disorders that require ongoing medical treatment”. Dr. Wentz made a motion to use the South Dakota language. Dr. Fiechtner and Dr. Cook both seconded. The motion passed.

### *Mental Health Conditions*

Tammy provided a brief report on available prevalence data. Frequencies of DSM-IV codes for 1,693 seriously emotionally disturbed children obtained from the ROAP mental health data system for SFY 2005 was reviewed. The top five conditions in terms of frequency were: attention deficit & disruptive disorder, depressive disorders, relational problems (parent/child), anxiety disorder, and bipolar disorder (mood disorder). CSHS receives many requests for ADHD and Autism, especially for coverage of medications. Sue Burns asked Medicaid staff for suggestions regarding mental health conditions. Their response was to add autism as families are struggling with what to do and how to treat their children. Dr. Cook suggested a team approach be available for diagnostic evaluations and that the team provide direction for where to receive treatment. Proper diagnosis is an issue. MeritCare has a team approach for evaluations. Some kids are referred out of state to the Dana Program at Mayo Clinic. More research by CSHS is needed on diagnostic criteria and best practice treatment standards (e.g.) Applied Behavior Analysis (ABA) or Treatment and Education of Autistic and Related Communication-Handicapped Children (TEACCH) model. Dr. Kerbeshian recommended CSHS contact Dr. William Barbanesi at the Mayo Clinic, as he is an autism researcher. CSHS could consider focusing on neuropsychological developmental disorders such as autism and ADHD. CSHS could also develop a multidisciplinary clinic using a collaborative approach. Staff could find out what other states are doing in this area. Dr. Wentz remarked that depression could also be considered because of the high suicide rate for teens in North Dakota.

Advisory council members were asked to complete the condition grid ranking potential new medical conditions.

### Covered Services and Reimbursement Issues

#### *Lack of Board Certified Providers for Neuropsychological Services*

CSHS requested a recommendation from the ND Board of Psychology regarding what criteria (e.g. licensure, board certification, specialized training, etc.) a psychologist should meet in order to provide neuropsychological services to children birth to 21 years of age. The board responded that it was not in their jurisdiction to dictate who can provide covered services. A CSHS eligible family that inquired about coverage for this service could not locate a provider with board certification in their area of the state and didn't think their health care network would provide a referral to another provider out-of-network when they had providers in-network. Input was solicited regarding what provider qualifications should be adopted if CSHS does not require board certification. Council members recommended that training required in order to sit for the national board be considered and that Neuropsychologists participating with CSHS have completed a fellowship in neuropsychology. Contact could be made with other child neuropsychologists in the state, especially those that are highly recommended by their peers, for additional information.

#### *Covered Services in Conjunction with Orthodontic Treatment*

CSHS has received inquiries regarding coverage of wisdom teeth removal for patients receiving orthodontic treatment. Currently CSHS covers dental exams and cleanings

during orthodontia and a final exam and cleaning after braces are removed as long as it is completed within six months. Dr. Sommers recommended coverage of additional services prior, during or after orthodontic treatment on a case-by-case basis depending on the specifics of the requested procedure and their relevance to orthodontic care. Considering all the landmines for case-by-case approval of coverage, it might be best to create a policy that does not include bridges, implants or bone grafting except under specific conditions. Examples include cleft palate, amelogenesis imperfecta, or dentinogenesis imperfecta. Such a policy would remove the seemingly arbitrary nature of case-by-case evaluation and focus resources on specific maladies. The advisory council endorsed suggestions made by Dr. Sommers.

#### *Revisions to the CSHS Medication Policy*

Medications, except those that are experimental, are currently covered by CSHS, which is similar to Medicaid's policy. Dr. Wentz recommended removing the term "Experimental Medications". Dr. Quanrud suggested adding "except in rare cases" to our policy and that medications used in investigational protocols could be covered on a case-by-case basis. Dr. Kerbeshian recommended that local Institutional Review Boards approve any investigational protocols. General consensus was that experimental medications generally not be covered unless they are used as part of an investigational protocol.

#### *Uncovered Services Requested in the Last Year*

CSHS staff have reviewed services that were denied over the past year. CSHS has denied respite care, communication devices, and transportation. Ideas regarding transportation assistance that were discussed included:

- Consider coverage of transportation assistance rather than full reimbursement for health related travel.
- Develop a fact sheet with available transportation options.
- Obtain information on Community Action as a resource.
- Set up some type of fund at a foundation level in order to help needy families.

#### *Experience Since Implementation of the \$20,000 Limit*

CSHS had one family in 2006 that met the \$20,000 limit and will likely have one family in 2007. The most recent child had Cystic Fibrosis. CSHS helped with medication reimbursement through the end of the child's eligibility month, which pushed the patient over the \$20,000 limit. CSHS covered the additional expense. The patient's medication costs were approximately \$4,000/month with an approximate cost of \$7,000 every other month. This family had no other health insurance coverage at the time. CSHS worked with the County Social Service staff, the social worker at the Coordinated Treatment Center, and the family. The children are now eligible for the Healthy Steps program with CSHS as a secondary payer. Other high cost conditions have included seizures and leukemia. To reach the coverage limit, families usually do not have a primary insurance source.

### *Adult Congenital Heart Clinic and Participation in the CSHS Cardiac Program*

MeritCare has recognized needs of transition-age individuals with congenital heart conditions. Dr. Rios sees young adults along with an adult cardiologist. This clinic helps these young adults transition to an adult cardiologist. CSHS allows young adults to participate in MeritCare's adult congenital heart clinic and participate in the Cardiac Care for Children program as long as the patients are under 21, residents of North Dakota, and their pediatric cardiologist is involved with the assessment.

Children's Heart Clinic in Minneapolis conducts monthly outreach clinics at Mid-Dakota Clinic in Bismarck. CSHS has seen increases in the number of children that participate in the Cardiac Care Program with this new outreach effort.

### *Coverage of Postural Orthostatic Tachycardia Syndrome (POTS)*

CSHS sees many children within the Cardiac Program to determine if their syncope is related to a cardiac condition. CSHS can assist families in obtaining a correct diagnosis. If it isn't related to a cardiac condition, the child is discharged from the program.

### *Medical Necessity*

The definition of medical necessity used by CSHS was included in the meeting packet materials. CSHS encountered a situation in which a young adult made many self-referrals to sub-specialists. Work ups on various significant illnesses such as leukemia and hemophilia were done without initial testing or discussion with the primary care doctor. In this case, some care was denied and CSHS staff asked the individual to involve her primary care physician for help with future referrals. CSHS does not currently have a formal appeals process. Instead, an administrative review process is outlined in policy. This process is used periodically if a provider or family member questions coverage decisions made by CSHS staff.

### Contract Services

Services expected to be funded for the next biennium include Multidisciplinary Clinic services, Care Coordination, Family Support, and Medical Home. Staff are in the process of obtaining revised proposal budget forms before initiating contracts within the Department of Health. More proposals were received than can be funded so some partial funding options will be considered this year.

### Programmatic Updates

#### *ND Early Hearing Detection and Intervention (EHDI) Report*

Sue reported that the ND EHDI program, which addresses newborn hearing screening, diagnosis, and follow-up was started April of 2000. Currently, 96% of all babies are screened at birth. Right Track is helping with follow-up of babies who don't pass their second hearing test. In 2007, all hospitals in the state used a web-based reporting system, which will support research and improve reporting of hearing loss in children. Border state babies that are born in North Dakota are included in this system.

### *Family Advisory Council Report*

Twyla Bohn reported that parents are now reviewing portions of the MCH Block grant. Families also participate in the ranking of family measures. She relayed that ND applied for a family stipend to enable a Family Advisory Council member to attend the Association of Maternal and Child Health Program (AMCHP) Conference, which took place in Washington D.C. Family members are advocating for new services. North Dakota was the first state to pass the Medicaid Buy-In program, an option that became available through the Family Opportunity Act. Families reviewed a draft of the Focus on Progress fact sheet, which included a real life family story.

### *Medical Home Report*

Tammy reported the following highlights on work addressing Medical Home:

- Collaboration – The Medical Home Team met periodically through the year.
- Funding – Support through the Early Childhood Comprehensive Systems (ECCS) and Head Start Collaboration grants was received and additional funding sources explored.
- Planning – Future Search, a community planning approach that acts on common ground, was explored. ND's Medical Home Team hopes to apply the model as the state progresses to implementation. Head Start funding was used to support this effort.
- Capacity-building - Professional development is being supported for parents, clinic managers, providers, and CSHS staff to attend the Future of Pediatrics national conference. ECCS and MCH Block Grant funding is being used to support this effort.

### *Transition Report*

CSHS staff worked with the Transition Council to plan the ND 2006 Interagency Secondary Transition Institute that was held October 2006. The CSHS focus was on health transition. A memorandum of understanding was signed with various agencies to collaborate in providing transition services to students with disabilities ages 16-21 in ND. CSHS staff continues to conduct annual health transition outreach mailings to CSHS families with transition age youth.

### *Asthma Report*

The State Asthma workgroup held a data meeting January 2007. Members of the workgroup continue to explore asthma reimbursement for certified asthma educators. An application was submitted for a CDC Public Health Preventative Specialist through the Department of Health. If selected, North Dakota would have staff assigned for a two-year field assignment in ND.

### System of Care for Children with Disabilities

Changes occurring in the system of care for children with special health care needs have a potential impact on CSHS. Recent changes affecting health care coverage include:

### *Waiver and Buy-In Program*

SB 2326 provided funding for a new Medicaid waiver for medically fragile children and a Medicaid buy-in program for children birth through age 18 meeting SSI disability

criteria up to 200% (net) of the federal poverty level. With the buy-in program, private insurance premium payments will offset the “buy-in” premium. The maximum premium will be 5% of a family’s gross income.

*Healthy Steps*

Flexibility with self employment allows use of the latest income tax information in the last three years rather than a three year average if there has been a big change in income.

*Medicaid*

Monthly income disregards will be added. Possibilities include \$50 child support income, \$30 work training allowance, health insurance premium for parents, etc. Continuous eligibility for Medicaid for children under age 19 means re-determinations will only be needed every 12 months. If the State Children’s Health Insurance Program is reauthorized, Medicaid eligibility may be increased from 100% to 133% of the federal poverty for ages 6-18.

With these changes, more children may potentially be eligible for Medicaid and Healthy Steps. CSHS would continue to gap fill as a secondary payer as the majority of clients currently being served have another source of health care coverage.

**CLOSING REMARKS/WRAP-UP**

Four of the five members with terms expiring agreed to continue. They include Dr. Sommers, Dr. Kerbeshian, Dr. Fiechtner, and Dr. Quanrud. Dr. Klava will be contacted to determine his interest.

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