



MEDICAL ADVISORY COUNCIL MEETING MINUTES

CHILDREN'S SPECIAL HEALTH SERVICES

May 20, 2006

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; Kora Dockter, Program Administrator; Leann Bayman, Eligibility & Claims Administrator; Denise Kirsch, Office Assistant; Diane Bruley, Administrative Assistant; Kathy Tschosik, Administrative Assistant.

Present as Medical Advisory Council Members: Gary Betting, MD; Thomas Carver, MD; Lois Freisleben Cook, MD; Jacob Kerbeshian, MD; William Klava, MD; Marcus Fiechtner, MD; Dennis Sommers, DDS.

Guests: Twyla Bohl, Family Advisory Council Member and Barb Schweitzer, North Dakota Department of Health.

Absent: Alan Kenien, MD; Amy Oksa, MD; Myra Quanrud, MD; Bruce Levi, North Dakota Medical Association; Joanne Luger, DDS; Terry Dwelle, MD, State Health Officer.

WELCOME & INTRODUCTIONS

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

DEPARTMENT OF HUMAN SERVICES (DHS) OPENING REMARKS

Maggie Anderson, Director of Medical Services, informed the Council there has been organizational, financial, operational, and program changes within the Division.

Organizational Changes

Dave Zentner retired in August, and Maggie was hired in August. In October, Carol Olson, the Executive Director of the Department of Human Services, decided to restructure the organization. Ms. Olson had about 20 directors reporting to her. The Governor felt this was too many so she created a cabinet of seven functional areas in the Department. The seven areas include Medical Services, Program and Policy, Institutions, Human Service Centers, Economic Assistance, Administration and Legal. This happened in October 2005 on paper and actually took place on January 1, 2006. Because of that change, Medical Services was also restructured and two Assistant Director positions were created. One position oversees Program Policy and the other focuses on Program Operations.

Financial Changes

Federal Medicaid Assistance Percentage (FMAP) is the percentage of money that the Federal Government provides for Medicaid, Medicaid Waivers and grants. In North Dakota, the economy is doing quite well. The down side of that is the FMAP then goes down. Medicaid is currently operating under a 65.85% FMAP. On October 1, 2006 that number will go down to 64.72% and on October 1, 2007 it will go down to 63.13%. For every 1% of change there is about a \$5 million per year general fund contribution to the Medicaid Program. Medical Services is watching this very closely. Because of this change, a \$22 million general fund contribution is needed just to keep the current services during the next biennium.

Operational Changes

Medical Services is moving forward with a new Medicaid Management Information System (MMIS). Costs are significantly higher than what was thought at around \$57 million. Medical Services knows that the system will save money over the long run, but it's a hard sell to the Legislature when the price tag almost doubled. Since the Legislature only convenes every two years, the Department does not have the additional monies to fund the whole project. The Legislative Budget Committee did agree to move forward with the project in phases. This will allow the Department to move forward until the Legislators convene for the next session. The questions on the table for the upcoming legislative session are whether the Department should rebid the contract or whether Medical Services can partner with another state. Medical Services is looking at a June 2009 roll out date for the new MMIS System.

Programmatic Changes

A large amount of time has been spent on Medicare Part D. Medicaid has a lot of clients who are dual eligible. This means they qualify for both Medicaid and Medicare. Implementation of Part D for Medicaid clients did not go very well. Clients were going without their medications and people were being charged large co-pays. There was massive confusion. The Department opted to continue to cover the medications of the dually eligible recipients until the problems were resolved.

Medical Services is interested in starting a Disease Management Program. A Request for Proposal (RFP) was issued. Four proposals have been received and were all scored yesterday. This will be a nurse driven case management type of program with a physician involved.

The overall goal of the Real Choice Systems Change Grants is to implement the Olmstead Decision and President Bush's New Freedom Initiative. The Department was awarded a Real Choice Rebalancing Grant, which addresses three key issues: (1) to rebalance state resources for services for the elderly, people with disabilities, and their families in strengthening self-directed services in communities; (2) to provide a single point of entry to services for the elderly and people with disabilities who are considering long-term home and community-based services and institutional services in North Dakota; and (3) to provide practical and sustainable public information services for access to all long-term care services in North Dakota.

A year ago, North Dakota had 2,300 children in the SCHIP Program and as of the first of the year there were 3,630. At the same time Medicaid lost about 200 children. Medicaid expects those 200 are now under the SCHIP Program because of some changes that were done with eligibility.

Overall, Medicaid is seeing a lot more of involved cases, a lot of requests for prior authorizations, and a lot of inquiries regarding long-term out-of-state issues.

Several Medicaid waivers are being worked on and revised. A new waiver is being written for children

with extraordinary medical needs. A vent-dependent waiver amendment is being explored as part of the aged and disabled waiver. This will have a self-directed component.

With the Deficit Reduction Act, there will be a lot of eligibility changes, mostly for long-term care. The focus is on home and community-based services instead of institutional placement. A Buy-in program is being looked at for children.

CHILDREN'S SPECIAL HEALTH SERVICES (CSHS) UNIT OVERVIEW

Administration

Tammy Gallup-Millner provided an overview of the CSHS unit. The mission for Children's Special Health Services is to improve the health of children with special health care needs and their families. CSHS receives a portion of federal funds that are separate from Medicaid. Children's Special Health Services is funded primarily through a Maternal and Child Health Services Title V block grant. A portion of this grant goes to the Health Department and the rest goes to CSHS in the Department of Human Services. The CSHS portion is directed just to the children with special health care needs population.

CSHS currently works with a staff of eight and Dr. Wentz as part-time Medical Director. Devaiah Muccatira is the newest CSHS employee. His job is to build data capacity for the MCH population.

The Title V grant funds services for the Maternal and Child Health population and totals about \$1.8 million. On the federal side, CSHS receives a little over \$600,000 for children with special care needs. The funding levels over the last five years have diminished slightly. CSHS also receives additional federal funding from an SSDI grant, which helps address data issues for the MCH population. CSHS operates on a \$1.7 million budget (federal and state funds) to provide direct services for children. The SSDI grant is \$132,000. CSHS also received \$150,000 in general funds this biennium for a Russell Silver Syndrome Program. Most of the Unit's funds are in the salary and grant lines. Grants fund claims payments, the metabolic food program, contract services, and the Russell Silver Syndrome program. Last year CSHS served about 1400 unduplicated children through various programs in the Unit.

Specialty Care Program

The Specialty Care Program is where CSHS actually pays for care for children. The caseload for this program is a little over 300 children. CSHS gap fills for children who have private health insurance. There are a lot of co-pays and deductibles that are not covered through private insurance. Financial eligibility remains at 185% of the federal poverty level, which equates to about \$37,000 for a family of four. CSHS continues to have the \$20,000 per year limit. This year, no clients met the limit. Presently, 93% of children served have a source of health coverage. Claims payments were highest for the following conditions: handicapping malocclusion, seizure disorders, diabetes, cleft lip and palate and heart conditions. For more specific information, refer to the FFY 2005 Claims Payment Report in the handouts.

Multidisciplinary Clinic Program

This is where the bulk of the children are being served. The multidisciplinary approach of care is considered best practice for this population of children. Families state these clinics are helpful and that clinics are much appreciated. CSHS has received a very high satisfaction ranking for these types of services. A high percentage of clinic recommendations are met. CSHS manages the cardiac, scoliosis and cleft clinics and then contracts for several other types of clinics. Scoliosis clinics are almost non-

existent at this point. Sue has worked very hard to try and get adequate providers, but orthopedists in our state are no longer comfortable seeing children at these clinics. They are a little more specialized than they were a few years ago.

Care Coordination Program

CSHS provides case management through county social services and continues to fund Care Coordination programs through two Public Health Units. There is a new care coordinator in Grand Forks. CSHS is also exploring the option of locating a care coordinator in a clinic practice to support the “medical home” concept. State staff assist with care coordination for children with more complex health needs.

Metabolic Food Program

CSHS provides formula and low protein food to individuals with phenylketonuria and maple syrup urine disease. This program continues to work well. There have been a few women that have become pregnant and have had normal pregnancies. Currently 22 clients are being served.

Information Resource Center

CSHS provides information and referral services to families free of charge.

Russell Silver Syndrome

CSHS is currently serving one client with Russell Silver Syndrome and has had an inquiry from another family about services.

APPROVAL OF MINUTES

Dr. Fiechtner moved to approve the minutes. Dr. Klava seconded the motion and all were in favor. The minutes were approved.

CERTIFICATION/RE-CERTIFICATION

Leann Bayman informed the Council she has been checking certification on CSHS providers. Some boards require recertification. CSHS currently has some physicians who have chosen not to recertify. The question for the Council is if physicians are not certified, should CSHS remove them from the provider list? In doing so, there may be children who are receiving services from that provider who we could no longer reimburse.

Dr. Fiechtner stated all boards do not require certification. A lot of hospitals require certification but ENT physicians are not required to recertify.

Dr. Kerbeshian suggested to not approve a provider for any new patients but approve them for current patients. Dr. Klava agreed.

Ms. Millner stated her concern is there is a lack of providers for serving these children and families

Ms. Bohl stated she would be concerned as a parent as to whom they would see if their doctor was not approved anymore.

Dr. Cook stated it is easy to recertify. She thinks any pediatrician that doesn't recertify should not be practicing. She agreed it differs by specialty but it's easy to get stale and not maintain quality.

The recommendation was to encourage recertification and don't let providers take new patients if they

are not recertified. CSHS could send a yearly reminder for people who have lapsed.

Dr. Wentz stated he was grandfathered in under Pediatrics but he chose to recertify. The first time he recertified he was able to do so by computer but now it requires traveling.

Dr. Cook stated she traveled to Bismarck to the Sylvan Learning Center and it took about 1½ hours.

Dr. Wentz stated if we notify physicians who do not recertify that CSHS cannot cover any additional kids, it might be an incentive for them to get recertified.

NEWBORN SCREENING

Barb Schweitzer, North Dakota Department of Health and Kora Dockter, CSHS, Department of Human Services reviewed short and long term follow-up currently being provided by both departments. See attached PowerPoint “Newborn Screening in North Dakota”.

The North Dakota Department of Health coordinates screening of all newborns, including coordination with local and primary health care providers and follow-up monitoring of all abnormal screens until a negative result or a confirmed diagnosis is received.

North Dakota Department of Human Services provides food and formula to individuals with phenylketonuria and maple syrup urine disease, state level care coordination, diagnostic and treatment services to eligible families and financially supports the metabolic clinic at MeritCare.

Since adding Cystic Fibrosis to the metabolic screen in January 2006, 19 children have had an abnormal cystic fibrosis screen. Four of those have been confirmed as having Cystic Fibrosis. The rest are carriers.

Ms. Dockter stated CSHS may be able to assist with the costs related to confirmatory testing for the conditions screened for in the North Dakota Newborn Screening panel. Some restrictions apply, one of which is CSHS must be contacted within 90 days of services. Ms. Dockter has received calls from upset parents who were not notified services were available.

Ms. Schweitzer stated she now mentions CSHS in her follow-up to physicians when she notifies them of abnormal screenings. Ms. Schweitzer does not receive the name of the family or their address when she receives the results. Physicians could give the family’s name and address to Barb, or Barb could send a letter to the doctor to mail to the family.

A question was raised about what to do if parents do not follow-up with an abnormal result and whether they should be referred to social services.

Some of the members advised that the State Health Department should report parents who don’t follow through with additional/repeat testing to social services for medical neglect.

Dr. Wentz stated we had discussion previously about several conditions where we had contact from the families looking for services.

CSHS MEDICAL ELIGIBILITY

Muscular Dystrophy

Ms. Burns reviewed the Muscular Dystrophy policy. There was discussion on why CSHS limited the types of Muscular Dystrophy that would be eligible. Dr. Wentz expressed concerns about this condition having so many forms. Dr. Klava was uncomfortable limiting the forms of Muscular Dystrophy that would be eligible. He thought CSHS would be approached to cover other forms of Muscular Dystrophy that are not on the list. Ms. Millner stated CSHS has received calls from different families regarding Spinal Muscular Atrophy, which is not included in the draft policy. Dr. Wentz asked the group if CSHS should cover Spinal Muscular Atrophy as well. Dr. Kerbeshian recommended CSHS cover the forms that are covered by the Muscular Dystrophy Association Clinic. CSHS could supplement only those individuals using Muscular Dystrophy Association Clinic services. CSHS could help at times when children need care outside of the clinic.

Eosinophilic Gastroenteritis

Ms. Burns reviewed the Eosinophilic Gastroenteritis Policy. There were no concerns with the policy as written.

Wegener's Granulomatosis

Ms. Burns reviewed the Wegener's Granulomatosis Policy. There were no concerns with the policy as written. The condition is considered more often than it is found.

REVIEW OF MISCELLANEOUS FILES AND SERVICE INQUIRES

The following are conditions that were denied medical eligibility by CSHS. The Council was asked their opinion regarding the eligibility decisions that were made over the last year.

Mental Health

CSHS has received inquiries for Attention Deficit Hyperactivity Disorder, Oppositional Defiant Disorder, Mood Disorder, Pervasive Developmental Disorder, Schizophrenia, Asberger's, anxiety disorder, and mild Tourette's. The coverage of these conditions has been brought up at previous Council meetings. It was decided at that time to only cover a mental health condition if it occurred as a result of the eligible condition (e.g. depression in a child with cancer). Ms. Burns asked if the Council still agreed that mental health disorders were a non-covered condition.

Dr. Kerbeshian stated you might want to look at more severe neuro psychiatric developmental disorders that affect the course of development (i.e. autism).

Dr. Klava suggested CSHS come up with exclusion criteria vs. inclusion criteria.

Dr. Kerbeshian recommended that the mission of CSHS be reviewed when making a decision regarding coverage of mental health disorders.

Severe Dental Caries

Ms. Burns stated CSHS received a request for a child with severe dental caries. This condition was not related to a congenital dental disorder or any other CSHS eligible condition that offers dental services. The child's dentist relayed that extensive amounts of bacteria were probably passed on from family members via sharing of silverware, cups, kissing, etc. The Council supported not covering this condition.

Other

Ms. Burns stated CSHS had a couple inquiries regarding conditions that are on the CSHS medical condition list but they were not at a severity that would be eligible. One request was for a child who

did not meet the criteria for moderate to severe asthma. Another was torticollis. The condition was not severe enough to require casting or surgery.

Additional conditions that were not covered include gastroesophageal reflux, kidney stones not related to an eligible condition, and balanitis, with a circumcision revision. The Council did not object to the denial of these conditions.

Condition Grid

Ms. Millner stated CSHS did initially use the condition grid when CSHS received some inquiries for currently uncovered conditions. Dr. Wentz picked three specialty physicians who had knowledge about those particular conditions. One of the things that CSHS found was that it was very difficult to get a timely response back from any of the people ranking the disorder. When CSHS received the responses back, all the conditions met the point criteria. The question for the Council is whether these conditions should be added to the list. Does this mean any new child that has the same condition would also be covered?

Ms. Millner stated she opted to delay any large-scale changes because of a Child Health Study going on in the Legislature. CSHS staff have provided interim testimony on children with special health care needs. Dr. Wentz also testified about the medical eligibility process. The Legislature is concerned about services for these children but they also know that there is a limited amount of funding available.

Ms. Millner stated she wants to wait to see if CSHS will get some direction from the legislature before proceeding further. CSHS has received no recommended changes at this point.

Dr. Cook stated the criteria in the grid are good.

Dr. Kerbeshian stated CSHS could look at resources, risk, gain, and impact and what is in the best interest of the group. If individuals need more than \$20,000 worth of care, maybe we shouldn't invest in those conditions. We need to look at equity and distributive justice.

Dr. Klava stated every child would be evaluated on a case-by-case basis in doing what Dr. Kerbeshian was suggesting.

Dr. Kerbeshian stated there might be some conditions where the \$20,000 investment ceiling would be a waste, because in order to have a meaningful outcome, they would need much more than \$20,000. The payback for that individual would be unknown.

Dr. Cook stated you might need to only have \$500 for a good outcome.

Dr. Wentz stated ethically it would be hard to communicate this approach to families.

COVERED SERVICES

Xolair

Ms. Burns reviewed the CSHS policy for Xolair coverage. A copy of the policy is part of the packet handouts. The Council did not voice any concerns with the policy and they agreed with the use of an

inhaled corticosteroid and another controller therapy, such as a long acting beta agonist or leukotriene receptor antagonist. They also agreed that a specialist should prescribe Xolair and that CSHS promote the use of the pharmacy assistance programs.

Pneumovest

Ms. Burns reviewed the CSHS policy for Pneumovest coverage. A copy of the policy is part of the packet handouts. CSHS chose to promote good management of the disease when deciding to cover pneumovests. There is not criteria to document a worsening respiratory status before the child would be eligible to receive a pneumovest.

Dr. Carver asked if this were a covered service for muscular dystrophy, would Spinal Muscular Atrophy be included?

Ms. Burns stated the pneumovest would be covered for conditions on the Muscular Dystrophy list, which currently does not include Spinal Muscular Atrophy.

Ms. Millner voiced a concern that the purchase of a pneumovest may take the child to their \$20,000 limit and then they would not be able to use CSHS funds for their daily medications. The Council did not voice any concerns with the policy.

Special Formula

Ms. Burns reviewed the CSHS policy for Special Formula. A copy of the policy is part of the packet handouts. The Council did not voice any concerns with the policy

Neuropsychological Services

Ms. Burns reviewed the CSHS policy for Neuropsychological Services. A copy of the policy is part of the packet handouts.

Dr. Kerbeshian stated there are a number of psychologists in the state who claim they are a neuropsychologist but actually are not. He supported the decision to require certification by the American Board of Clinical Neuropsychology (ABCN) or the American Board of Professional Neuropsychology (ABPN)

OTHER COVERED SERVICES

Ms. Burns stated some of the other covered services issues CSHS has had are:

1. Over-the-counter-medications

CSHS reimburses some over-the-counter medications if they are used to treat the medically eligible condition (i.e. vitamins for children with cystic fibrosis, Claritin for children with asthma, Glutose for diabetes).

2. Medicaid Gap Filling

Ms. Burns stated CSHS has done very little Medicaid gap filling. The most common area is orthodontia. CSHS requires more points than Medicaid for handicapping malocclusion. A prime example is children with cleft or handicapping malocclusion who typically have a longer and more complicated course of treatment, so the provider requests a higher reimbursement than Medicaid allows. When working with children that have had a cleft, the timing of the orthodontia is critical. If it is not done at the correct time, the child may need jaw surgery. CSHS also considers the distance the family would have to travel to see an orthodontist that

accepts Medicaid reimbursement when making decisions regarding coverage.

3. Ectodermal Dysplasia

Ms. Burns stated the children who have ectodermal dysplasia have been a struggle. CSHS staff have put a lot of time into care coordination for these children. It's been hard to access specialty dental care that these children need using a coordinated approach. Some families have opted to go out of state. There may be a need for provider training and further exploration regarding dental insurance coverage.

NON-COVERED SERVICES

Ms. Burns reviewed some of the requests that were not covered through CSHS.

1. A family was looking for respite care for their child with cystic fibrosis. CSHS does not cover respite care at the present time and likely will not expand services in this area.
2. A family was looking for soy formula for a child with galactosemia. Because this was a typical infant formula, CSHS did not cover it.
3. CSHS received a request for a child with a seizure disorder to receive IV gamma globulin as part of their treatment plan. The drug was not FDA approved to treat seizures so it was not covered by CSHS.
4. CSHS received a request for a coagulation monitor for a child with a cardiac condition. The family wanted to have their own coagulation monitor so they did not have to drive to a clinic. Since monitors are not FDA approved for home use, CSHS did not approve the monitor.
5. Ms. Burns stated CSHS does not cover a lot of Durable Medical Equipment (DME) items. Some DME items CSHS does cover are nebulizers, insulin pumps, cochlear implants, hearing aids and wheelchair rentals.

PROGRAMMATIC UPDATES

Asthma

Ms. Dockter stated the Legislature passed a law allowing students to self-administer medication. Refer to the packet handouts for information regarding web training and asthma action plans.

First Sounds

Ms. Burns stated she has worked with the First Sounds project, which is the North Dakota Early Hearing Detection and Intervention project, since it began in 2000. CSHS is working collaborately with the North Dakota Center for Persons with Disabilities at Minot State University. This program provided equipment to each birth hospital for newborn hearing screening, training, and a web-based data collection system for reporting. Minot State University has also received a Centers for Disease Control grant to further follow-up through the Parent-Infant Program and Early Intervention System. Quarterly newsletters are available. Legislation is being considered. One Council member relayed that organized medicine would likely be against an unfunded mandate.

Family Advisory Council

Ms. Bohl stated she likes sitting on the Family Advisory Council. Council members have used the new Maternal and Child Health definition of family centered care to create awareness and educate the public. This was done with the help of Donene Feist through the Family Voices newsletter. CSHS shared new waiver service recommendations from Family Advisory Members with the Medical Needs Task Force. Respite, Medicaid access and care coordination are supports families are looking for. CSHS continues to have family support partners attend annual clinic coordinator meetings. Ms. Bohl

stated she attends one of the specialty clinics in Grand Forks.

Medical Home

Ms. Dockter stated CSHS is promoting the medical home concept in North Dakota, an AAP initiative. Staff are currently looking for four to eleven primary care providers who will commit to implementing the medical home concept in the state. The North Dakota Medical Home team met with the Minnesota Medical Home Team. Staff are planning a Medical Home Steering Council meeting to develop a state plan.

Transition

Ms. Dockter stated she sits on the state Transition Steering Council. The Department of Public Instruction (DPI) is putting on a transition conference in October. CSHS provides an annual health focused transition mailing to CSHS clients ages 14-21. CSHS has found young adults with a chronic health condition sometimes drop off their parents' insurance and experience a lapse in coverage. They can end up with waiting periods or be unable to qualify for health insurance.

Russell Silver Syndrome

Ms. Millner stated CSHS currently has one child covered under the Russell Silver Program; however, additional families are showing interest in the services. The program has gotten off to a slow start. Ms. Bayman stated claims presently are between \$5,000 to \$6,000. Ms. Millner stated Russell Silver Syndrome is an expensive condition, as children may need growth hormone treatment and special formulas.

System of Care

Ms. Millner stated that Legislators are conducting a Child Health Study. The study may impact some policy and programs that support families in our state. A lot of families need financial help. A Medicaid Buy-In program could potentially meet that need. For some of the children that have a more severe disability, a Medicaid waiver program would give them access to the Medicaid state plan and also some supportive services that families need to keep their children at home. It is unknown if either of these options will be funded during the next session. Ms. Millner stated CSHS has received a lot of feedback this year regarding access to pediatric service providers. It has been difficult for families to access pediatric specialty care. Ms. Millner stated CSHS has seen some increase in families using the Shriner's services.

CLOSING REMARKS/WRAP-UP

Dr. Wentz thanked everyone for their participation and reminded everyone to complete their reimbursement forms.

Membership terms are up for Dr. Carver, Dr. Kenien, Dr. Cook and Dr. Oksa. Dr. Klava recommended CSHS contact Dr. Haasbeek regarding membership. Dr. Wentz asked if everyone was willing to serve another term. Dr. Carver agreed. Dr. Wentz stated CSHS tries to look at membership geographically. Dr. Kerbeshian suggested looking at adding Pediatric Neurology. Dr. Kenien and Dr. Cook will be contacted to determine their interest.