



**Children's Special Health Services
Medical Advisory Council Meeting**

**Comfort Suites – Meeting Room A
Saturday – May 2, 2009
8:30 a.m. to 12:00 noon CDT**

Present from the ND Department of Health (DoH): Terry Dwelle, MD, State Health Officer and John Baird, MD, Special Populations Section Chief, North Dakota Department of Health

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; Tricia Kiefer, Program Administrator; Melissa Evans, Eligibility & Claims Administrator; Denise Kirsch, Office Assistant; Diane Bruley, Administrative Assistant; Alicia Phillips, Administrative Assistant.

Present as Medical Advisory Council Members: Thomas D. Carver, MD, Heidi Goldstein, MD, Sue Karen Wink, MD for Marcus Fiechtner, MD, Jacob Kerbeshian, MD, John Warford Jr., DDS for Dennis Sommers, DDS, Robert Kemp, MD, Myra Quanrud, MD, John Martsolf, MD, William Klava, MD, Gary Betting, MD, Joanne Luger, DDS, Evelyn Klimpel, Family Advisory Council Designee

Present as Guests: Kora Dockter, ND Integrated Services Project Director.

Absent: Jacqueline Quisno, MD, Sandeep Batra, MD, and Bruce Levi, North Dakota Medical Association Executive Director.

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

Terry Dwelle, MD, State Health Officer and John Baird, MD, Special Populations Section Chief, thanked Children's Special Health Services staff for the leadership provided on behalf of the children with special health-care needs population and relayed appreciation to all members for attending the meeting.

CSHS DIVISION OVERVIEW AND UPDATE

Tamara Gallup-Millner provided an overview of the CSHS Division. The Division'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. Joan Connell, who became the new CSHS Medical Director in January 2009. Dr. Wentz, the previous Medical Director, resigned last July due to health problems and passed away on January 3rd of this year. In addition to state staff, CSHS also utilizes social work professionals at the 53 county social service offices to help with eligibility and care coordination activities.

CSHS administers MCH Title V Block Grant funds devoted to children with special health-care needs. CSHS shares funding from this federal grant with other divisions in the Department of Health. The CSHS Division budget for the 2007-2009 biennium, which is a combination of federal and state matching funds, is about \$2.4 million. A similar budget is expected for the upcoming biennium.

Tammy shared some programmatic highlights and reviewed some of the handouts in the meeting packet. The Birth Defects Surveillance report and the State of Health report that focuses on the children with special health-care needs population in our state was mentioned as a possible handouts of interest. A report of all medical conditions that CSHS serves is also included in the handouts. CSHS serves about 2,000 children per year. Ninety percent of the children served have a source of health-care coverage and CSHS is doing the gap filling.

Tammy provided an overview of the CSHS programs.

- The **Specialty Care Diagnostic and Treatment** program helps pay for medical care for children who meet CSHS eligibility requirements. It can be used to help diagnose children if they do not have a known diagnosis and is also used to help pay for their treatment.
- Most of the children served by CSHS through the **Multidisciplinary Clinics** and/or specialty clinics. Examples of some of the clinics are the Cardiac Care for Children Program, Cleft Lip and Palate Clinic or Asthma Clinic. These clinics are provided until the child transitions into adulthood.
- CSHS provides formula and low protein modified food products through the **Metabolic Food** program for the children who are diagnosed with PKU or MSUD.
- The **Russell-Silver Syndrome** program is a special program that the legislature added a couple of sessions ago. This program provides growth hormone treatment and medical food for children with this syndrome.
- CSHS provides services through the **Care Coordination** program. Children with complex health conditions often need different care from different support systems such as medical care, family support services, and community based services. A lot of work goes into linking families to these types of resources in the state.

- A **Resource Library** is maintained within the division that provides information to families.
- The **CSHS Data System** provides data about the population of children with special health-care needs and their families through the State Systems Development Initiative.
- The **Children with Special Health Care Needs Service System** is working on special projects such as making the service system a more family centered program and expanding Medical Homes, which plays a large part in trying to enhance primary care for children with special health-care needs.

To explain the program, Tammy provided a scenario that shows how a child typically enters the system and how CSHS is able to assist the family. When a parent calls CSHS about their child who has asthma, they are not quite sure what they are calling for, but were referred to us for help. CSHS staff will do some screening on the phone to see if the child might potentially have a medically eligible condition. A medical report is requested to be sent to the CSHS office to thoroughly check on medical eligibility and to have the appropriate documentation of the child's condition. Once the medical report is received the Medical Director reviews the report and makes the medical eligibility determination. This report is also used to screen for any potentially eligible conditions. Many times there are other conditions besides the initial condition that may be eligible for coverage. CSHS staff will review financial eligibility levels with the family in an effort to fit them with the services that will benefit them the most. Families are always encouraged to apply even if the eligibility levels may be below their income level as families can be eligible with a cost-share. There are also methods to help a family spend down their cost share such as using their health insurance as a deduction if they are paying out-of-pocket premiums. A lot of state level care coordination is conducted on the phone as well. If the family is interested in applying they are then directed to their local county social service office. There is an individual in every county office that works with the CSHS program. This person will help them go through the application process and is meant to be a helping person to that family. If the family is eligible both medically and financially, the social worker will also help them with the care coordination service plan and help with the linkage at the local level. Care coordination can also be done at the state level (e.g., linking the family to appropriate providers, linking to an early intervention program, or family support services). The eligibility process has to be completed on an annual basis, but there is no discontinued coverage throughout the year.

It was noted that financial eligibility is not required for Diagnostic Services. To be eligible for Treatment Services the family must meet the financially eligibility requirements. The legislature has set the CSHS financial eligibility at 185% Federal Poverty Level.

A legislative update was provided. In the Health Department's Appropriation Bill, limited to CSHS, there is a base budget of about \$2.7 million, but it has not passed yet. The possible changes that were being considered for the division were to reduce the funds for the Russell-Silver Syndrome program from \$100,000 to \$50,000. The law requires CSHS to pay up to \$50,000 per child per biennium. Currently the two children that are being served have insurance and we are gap filling so we are not using the full amount. There is talk about reducing the optional budget request for the Specialty Care program services by \$50,000 from \$88,000 to \$38,000. There was consideration to add \$50,000 for Newborn Hearing Screening which was advocated for about \$160,000 annually. \$50,000 would not be sufficient to support a program and staff. The funding could be used to help support changes to the immunization data system to include hearing screening results. Primary care providers would be able to access this system when an infant is seen for a well-child appointment and know which infants have passed their newborn hearing screening and which infants require additional follow-up. The Department of Human Services bill includes rebasing for providers so that the reimbursement is closer to what

costs are and also covers inflationary increases. There is some funding included for an autism waiver and they did consider increasing some of the medically needy levels for Medical Assistance, which may help serve more children in the state. There has been a concern with the Children's Health Insurance Program bill. The governor's budget had increased eligibility to 200% of poverty so more families could qualify. The latest version of the bill is at 150% of poverty and there is some movement to increase it to 160% of poverty, but that is probably as far as it will go. The bill did include money for out-reach, however. There has been a lot of interest in transition, in regards to the movement from pediatric to adult health-care milestones. Staff has been looking at some opportunities for transition age youth at risk and a youth council. There was an autism bill that was passed that created a task force around autism and a responsibility to develop a state plan. That state plan would allow agencies to apply for federal grants. There was funding for a Fetal Alcohol Syndrome Center. There have been multiple dental bills that have passed such as dealing with licensing, some dealing with the dental care-mobile and the dental loan re-payment. There also may be a potential health insurance study conducted. Some of these bills do not have closure yet; however, they should be finalized in the next couple of days.

BUSINESS

Dr. Connell asked if there were any comments or questions regarding the 2008 minutes.

Dr. Kemp inquired about the recommendation that CSHS only require board certification at the time of enrollment. Dr. Kemp felt it should be similar to any credentialing process at any hospital which requires current board certification.

It was explained that CSHS had a concern about the interruption of care for children who had an ongoing relationship with a provider over time as well as a concern that there may not be enough qualified providers. It was noted that there are very few physicians that are not recertifying.

Minutes: Dr. Kemp moved to approve the 2008 meeting minutes. Dr. Lugar seconded the motion and all were in favor. The minutes were approved.

CSHS Medical Eligibility

Report on activity after addition of syndromes to the CSHS medical condition list effective 1/1/2009

Dr. Connell reported that CSHS has had only one application for the condition of syndromes, a child with Turner Syndrome. The only service CSHS is currently providing this child is estrogen replacement. The criteria handout that CSHS uses to approve a syndrome was provided to each member who clearly showed Turner Syndrome fulfilled the criteria. Dr. Connell specifically asked Dr. Martsof for his opinion and opened it up to others who may have comments or thoughts on the criteria. Dr. Martsof stated that there are syndromes that aren't treatable now, but may be in the future. He also stated it is good to have criteria because that way it can be explained to the family why it is or isn't covered. He was concerned about the broad criteria. Dr. Quanrud stated she was not aware that syndromes were covered and said CSHS may be able to cover diagnostics, but when treatment kicks in there may not be much that can be covered. Dr. Kerbeshian stated that we have individuals who have certain needs who meet the functional pattern consistent with a child with special health needs and we do have an illness that is chronic and which fall within the broad range of what these syndromes have in common in terms of the developmental consequences and social consequences. When CSHS is notified of a child staff will bring the syndrome that they happen to have to the Medical Advisory Council, which approves and then adds that condition to the list. Essentially what is happening is there is

post hope gratifying due to programmatic requirement, a different process, and that process is what we are looking at in meeting children's and families needs functionally. By adding syndromes to the list with the new method, it is a pro-forming activity. You could do away with it and still function just as well or you could keep doing it because it is pro-forming.

Sue Burns contacted the South Dakota Health Department to find out how they handle syndromes. When South Dakota receives an application for a child with a syndrome, they have a medical team review the syndrome to see what eligible conditions are within that syndrome. For example, if a child has Down Syndrome, the medical team looks to see if the child has a cardiac defect, hearing loss etc. and they piece-meal it together in the same way CSHS did before adding syndromes. However, South Dakota will not cover anything that affects development, such as occupational therapy, speech therapy, physical therapy, etc. They leave that to the schools and early intervention. Because the developmental part is not being covered, they have been able to fit the condition under other diagnoses (e.g., cardiac, hearing loss) and therefore, South Dakota doesn't have any children eligible under syndromes.

Dr. Connell suggested that this topic be brought up again next year when there may be more cases to observe so there can be more of an objective discussion on how things are going. Sue Burns mentioned that CSHS has had trouble with some diagnostic testing. There are some out-of-state labs will not enroll with government programs so CSHS is not able to pay for the diagnostic tests that they completed. There is not a lot CSHS can do to help the families if they are in that type of a situation. Dr. Betting inquired about medical necessity and if CSHS would cover testing if the results didn't change the treatment course. He also inquired if there was a limit on diagnostics covered. CSHS does have it stated in the policy that testing needs to be medically necessary and there is a maximum of \$20,000 per child per year.

Dr. Klava asked if the \$2.4 million dollars is all spent or if CSHS is trying to ration what is spent. Tammy stated that most of the money is spent. There is some that is un-obligated, mainly through some of the contractors we work with for clinics who don't spend down all of their money, but it is obligated and therefore cannot be used for another purpose. Tammy explained that CSHS tries to ration with the \$20,000 dollar limit. That is considered our safety net.

Advice regarding potential gap areas in CSHS medical eligibility identified during the year:
CSHS has received requests for Autism spectrum disorders, Krabbe Disease, Lyme disease, Malignant hyperthermia, ADHD, ODD, Mood disorder and mild Asthma.

Autism spectrum disorders-

Dr. Quanrud stated that this condition should be covered due to the high incidence; however the services alone would break the bank. She inquired on what would be covered (e.g., OT, PT). It is hard to provide everything that should be covered (e.g., psychological screening). One way CSHS could help with coverage would be through a Multidisciplinary Clinic. This will provide some assistance while also contain the cost. This clinic may have to be a mobile clinic that would be able to serve 3 to 4 sites. It would be very hard for families around the state to make it to one site location. Tammy stated that CSHS did receive a Request for Proposal for an autism diagnostic clinic that would function in 2 communities in our state. CSHS is considering funding this clinic. Dr. Martsolf said that finding a diagnosis of autism is easier than determining the etiology. Dr. Klava wondered if finding the etiology would change the treatment. Dr. Kerbeshian feels the name of "Autism Spectrum Disorder" should be changed because it is too broad and confusing and the name is not an agreed upon term in literature. He feels it is equivalent to pervasive developmental disorders. Dr. Goldstein asked about the function of the clinic. Is it for diagnostics? Tammy said the clinic would be helpful in the management plan. There would

probably be some pre-screening parts to make sure that the child really should have the opportunity to go through the assessment process and then they would look a little more at management and working with the community to try and help the child better. Dr. Betting asked if the family would have to be referred to the clinic. Tammy said that the clinic coordinator would be the one to assess if this would be the right fit for the child and the family. This would be a new service as of July therefore some of the bugs will be worked out, but based on the proposal this is what was being stated. Dr. Carver asked how often the clinics would meet. The proposal stated the clinic would be twice a year in each site. Tammy noted that North Dakota is looking legislatively at a plan, a task force, a waiver, etc. to help children with autism. She asked council members if now is the right time to enter into the coverage of this condition or is it better to wait and see what happens with the other activities before a decision is made. Dr. Quanrud asked if CSHS should explore more of the mental health and behavior conditions. Sue Burns pointed out that CSHS has received a few phone calls requesting assistance with medication expenses related to mental health conditions. Dr. Connell asked that since there is a task force for autism would it be a better use of our time to get involved with the task force so we can help steer where it goes because of our advocacy experience? Dr. Klava felt that the autism spectrum disorder could be lumped with the mental health conditions such as Rett Syndrome and childhood disintegrative disorder. Dr. Kerbeshian disagreed with this because of the concept of the autism spectrum part. This throws you in with the broad range of ADHD, mood disorder, etc. Part of the problem would be the mudding of the diagnostic criteria over time in particularly throwing many of those children's whose conditions we traditionally treat here into the broad spectrum disorder. Dr. Connell asked if Rett Syndrome and disintegrative disorder should be used as the disease states that we should cover. Dr. Klava felt these should be covered but not limited to just these. The children with mental retardation, IQ below 80, and severe developmental delay could be considered as well. Dr. Quanrud felt, however, it is too hard to test the IQ of a young child, but could we label it by the severity of the disease as far as the eligibility side. Dr. Kemp felt CSHS should wait with the addition of autism and wait to see the results of the task force.

Dr. Kemp made a motion to obtain more information with the use of the diagnostic multidisciplinary clinic and our involvement in the autism task force and bring it up for discussion in a year. Dr. Wink seconded the motion. All were in favor.

Krabbe Disease-

Dr. Connell referred everyone to the blue handout in the packet. The handout is a letter from a mother whose child was recently diagnosed with Krabbe Disease. The mother was asking for Krabbe Disease to be added to the CSHS Medical Condition List. Advisory Council members were asked to complete the CSHS medical condition grid for Krabbe Disease to provide an object view of this condition. Dr. Kemp stated this condition is very easy to miss until it is too late, especially for the rural communities that do not have the skilled people to pick up on the subtleties of this disease. Dr. Martsolf doesn't feel there is an effective treatment for this right now. Dr. Connell had contacted Dr. Sara Copeland, the metabolic physician in charge of the newborn screening program at the University of Iowa, to get her thoughts on Krabbe Disease. Dr. Copeland stated New York State is the only state that has newborn screening in place for Krabbe Disease. Illinois may implement screening in 2010. Dr. Copeland is opposed to screening for Krabbe Disease since there isn't a good evaluation. She shared three papers that show that there continues to be a progression of the illness even in young infants that have been transplanted prior to exhibiting symptoms of the syndrome. Dr. Copeland is opposed to adding this condition to the newborn screening panel because there isn't a good treatment that is curative. Dr. Connell asked if this would still meet the philosophy of a CSHS covered condition? Dr. Quanrud feels that Children's Special Health Services should at least cover the diagnostic

services for Krabbe Disease. Dr. Betting suggested that we use leukodystrophy instead of Krabbe's disease.

Dr. Quanrud made a motion to approve the addition of leukodystrophy to the list of CSHS covered conditions and Dr. Klava seconded the motion. All were in favor.

Lyme Disease and Malignant Hyperthermia-

Advisory council member were asked if Lyme Disease and Malignant Hyperthermia should be considered as eligible conditions. The members decided against adding the conditions as they are not chronic in nature.

Dr. Kemp moved to deny the addition of Lyme Disease to the eligible condition list and Dr. Carver seconded this motion. All were in favor.

Dr. Klava moved to deny the addition of Malignant Hyperthermia to the eligible condition list and Dr. Kemp seconded this motion. All were in favor.

Mental Health conditions ADHD-

CSHS has had requests for assistance with obtaining medication to treat ADHD. Dr. Kemp feels there is a huge non-compliance issue with the medications because of the costs. Dr. Connell discussed the possibility of paying for the evaluation under Diagnostic Services, and/or the treatment services for children that meet the 185% poverty level criteria. Dr. Kerbeshian feels the diagnosis should be made by a clinician prescribing the medications.

Dr. Quanrud moved to approve the addition of ADHD to the eligible condition list and Dr. Kemp seconded the motion. All were in favor.

Mental Health conditions ODD and Mood Disorder

There was discussion regarding adding other mental health conditions when CSHS is considering adding ADHD. There was concern about adding too many conditions at one time.

Dr. Kerbeshian moved to deny the addition of ODD to the eligible condition list and Dr. Klava seconded the motion. All were in favor.

Dr. Kerbeshian moved to approve the motion that we do a trial with ADHD before adding other mental health conditions as that is more measurable and Dr. Kemp seconded this motion. All were in favor.

Mild Asthma-

Dr. Connell directed everyone to look at the green asthma handout that was provided. For CSHS Treatment purposes, asthma is defined as persistent asthma under the criteria on the handout. According to the guidelines, there are two types of asthma, mild intermittent asthma and persistent asthma. It has been decided CSHS would only provide treatment for the children who had persistent asthma as they would benefit from preventive controller medication (i.e. steroid inhalers).

Dr. Kemp moved to deny the addition of mild asthma to the eligible condition list. Dr. Carver seconded the motion. All were in favor.

Dr. Quanrud moved to accept the amendments to the CSHS policy draft regarding persistent asthma and Dr. Wink seconded this motion. All were in favor.

Heart Conditions-

Dr. Connell reviewed a policy draft for heart conditions (green handout). The coverage of services had not changed. There was only wording clarification in this new policy draft.

Dr. Quanrud moved to approve this motion and Dr. Martsolf seconded this motion. All were in favor.

Scoliosis-

Dr. Connell reviewed the policy draft for the condition of scoliosis (green handout). This section of the policy manual is being re-written as Children's Special Health Services is no longer holding scoliosis clinics. Upon reviewing the policy, Dr. Klava recommended that the orthopedic doctor wording be changed to a musculoskeletal specialist.

Dr. Quanrud moved to approve this wording change and the policy and Dr. Klava seconded this motion. All were in favor.

FINANCIAL ELIGIBILITY, COVERED SERVICES AND REIMBURSEMENT ISSUES

Dr. Connell stated that currently financial eligibility for CSHS is mandated at 185% of the federal poverty level. Tammy stated that this percentage is mandated in the North Dakota Century Code; therefore, any changes to this would need to go through a legislative process and it is not a policy decision that CSHS can make. At this time it equates to about \$40,700 for a family of four. CSHS uses gross income when assessing the eligibility. If a family self pays their health insurance premiums, they can use that as a deduction. For the most part, CSHS is a secondary payer that fills the gaps for what insurance does not cover (e.g., co-pays, deductibles, uncovered services, etc). Some families can be above the 185% but then they will have a cost-share each month. There is a lot of literature right now about the concern regarding the increasing financial burden for families. The child with special needs may be using a disproportionate amount of the family's income. The family may have additional health needs that are not being met. Sue Burns added that CSHS has been at 185% since 1999 and the level has not risen. The WIC program is also at 185%. The eligibility level may look like it is higher than the Children's Health Insurance Program (Healthy Steps), but this program uses net income and CSHS is gross; therefore, there really is not much difference between the programs. Evelyn Klimpel stated that she would like to see the eligibility level for CSHS raised to 200%. Melissa Evans shared some statistics on the families that are over the CSHS financial eligibility level. The family cost share per month is anywhere from \$40 per month to over \$3,000 per month. If it was raised to 200% based on a family of four it would affect about 7 to 8 families. If it was raised to 225% it would affect about 20 families. There is quite a range of cost shares per month.

Dr. Kemp moved to approve that the financial eligibility level for CSHS be raised to 200% FPL and Dr. Carver seconded this motion. All were in favor.

COVERED SERVICES

Sue Burns relayed that a \$20,000 limit, per child per year, was implemented about 5 to 6 years ago. These children may have multiple conditions that meet the eligibility criteria and the limit would be for all the care the child receives through the diagnostic and treatment program. The eligibility date starts from the time of the application to 365 days later when they would need to apply again. The application cycle is once per year. Looking at the federal fiscal year from October 2007 through September 2008 CSHS paid \$5,000 or more on a total of 4 children along with 8 children who had payments in the \$3,000 to \$5,000 range. The remainder of the children served through our program has had payments below the \$3,000 total. The large majority of

these claims are for the co-insurance, co-pays and the gap filling. The children that have reached the \$20,000 limit have had a seizure disorder, cystic fibrosis or cancer. In the last year the higher payment amounts were due to cancer, dental disorders, hearing loss and cleft lip and palate. A few of these children did not have any source of coverage; therefore, these families had a gap in their coverage and CSHS was able to help fill in. From the federal level CSHS is being directed to do more population-based services. In ND, CSHS is still seeing a need for direct services (i.e., payment of care). At times CSHS struggles with the decision to continue to provide direct service or should more funding be put toward clinic services. Dr. Connell stated that if CSHS starts to broaden the number of conditions being covered and is able to increase the income eligibility level, CSHS may begin to notice a pinching of the funds and then we will have to adjust those issues. Dr. Baird stated that this may be a compromise if we have to go to the legislature and ask for 200% of poverty and in turn we may have to lower the per child limit to \$15,000. CSHS would like to cover more children but may not be able to do the occasional catastrophic case.

Requests for covered services-

Sue went through the covered service requests from the previous year (pink handout). The sleep study for a child who was eligible for ectodermal dysplasia was denied because it was not related to the child's eligible condition.

Questions have come up regarding replacement for orthodontic retainers after the treatment has been completed. CSHS feels strongly about not replacing a retainer for a child who was not wearing their retainer. If the child is not being compliant with the follow-up treatment plan CSHS does not have the responsibility to purchase another retainer. CSHS has replaced a retainer, however, for a child who wore hers for 5 years and it has just worn out. CSHS did agree to cover one replacement retainer if there is documentation that they have been compliant with the follow-up treatment.

CSHS has only paid for a cochlear implant for one child and she is now doing a second implant. Cochlear implants have been handled on a case-by-case basis. Advice was requested as to whether CSHS should cover one or two implants. This child is our only experience with cochlear implants and this family has insurance and we have not had a huge cost on our end. Dr. Wink stated a person does not qualify for a cochlear implant if they can still use a hearing aid. She felt that covering one cochlear implant in the future would be sufficient.

CSHS approved coverage for the removal of an ingrown toenail for a child with diabetes because it was getting infected. This has been handled on a case-by-case basis at this point.

The Postural Orthostatic Tachycardia Syndrome (POTS) has been covered under heart conditions. We have had a couple of children who have asked for services related to the POT Syndrome and because it is an autonomic instability it really effects and causes tachycardia and postural hypotension. This is typically dealt with by cardiologists and with Dr. Connell's review we felt it was appropriate to still cover this under the heart condition.

Dr. Connell did a review of the policy for heart conditions and agreed that CSHS will cover pacemaker checks under both diagnostic and treatment services. This service can be covered under the diagnostic program if Children's Special Health Services did not pay for the placement of the pacemaker. This can be done as the pacemaker will be evaluated as well as the status of the child.

The Metabolic Food Program will provide PhenylAde 60 as one of the formulas that are offered through the program. This product has fewer calories and the child would need to drink a smaller volume of the product to get the necessary protein, although the nutrient content isn't as great as the other formulas. Cathy Breedon recommends supplements for all children with PKU so she isn't as concerned about the nutrient value. Dr. Betting feels that a generic formula should be used unless the name brand formula is needed. There was also discussion regarding the coverage of Camino Pro, an amino acid product used in the treatment PKU and MSUD. There were concerns with the cost of this product (almost double that of the traditional formula) and the convenience packaging. Dr. Kemp suggested CSHS pay for PhenylAde 60, then have the family apply for CSHS Treatment services if they would like the more expensive formula. It was agreed that CSHS should develop a list of base products it could provide through the Metabolic Food Program and what could be covered under Treatment Services.

A family has requested assistance with low-protein modified food products for their child that has a urea cycle disorder. Currently their insurance is covering the specialized formula that is needed. CSHS is not able to provide the low-protein modified food products since they are only covered under the Metabolic Food Program. The state mandate restricts the eligible conditions to Maple Syrup Urine Disease and PKU. Dr. Connell had spoken with Cathy Breedon about the metabolic food and she stated that these diets make compliance difficult, if this will increase compliance, she recommended providing it. Dr. Kemp asked if Cathy would be able to come to the Medical Advisory meeting next year to explain metabolic food in more detail. He also asked for more information on the metabolic food for his own knowledge.

REIMBURSEMENT ISSUES

Tammy provided a report on reimbursement issues including anticipated rebasing and inflationary increases for providers. Rebasing percentages have varied through the session. The most recent numbers show that hospitals would be reimbursed at 100% of cost, dentists at 70% of average billed charges, but the may increase to 75% and physicians at 20% of cost, although it may be increased to 75%. There was also discussion regarding a 6% inflationary increase to all providers. The above mentioned providers would only received the inflationary increase the second year.

SYSTEM OF CARE FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS

Tammy gave a warm welcome to Kora Dockter; Director of the Integrated Services Grant (NDIS). Kora was invited to give a brief overview of the Integrated Services Grant along with an in-depth discussion regarding the Medical Home Learning Collaborative, an approach to enhance primary care for children with special health care needs. Kora reviewed the North Dakota Center for Persons with Disabilities Integrated Services web site that just went live (www.ndcpd.org/ndis). NDIS is a 3-year grant project; the first year will be completed at the end of May. Some of the project goals are to create a learning collaborative in 3 primary areas: Medical Home, healthy transitions of youth to adulthood and working on family involvement and cultural competency. There are Medical Home pilot programs that are being established across the state. The pilot site will begin to work on a comprehensive plan to integrate these services into the current service system. There is a push to go with more systems development rather than direct services. The project is hopeful that they will be able to identify other funding sources and possibly some other ways to extend their work rather than expecting the state system to incorporate this into their current work load. Drs. Quanrud (Jamestown) Carver (Minot) and Petty (Devils Lake) are the current Medical Home practice sites. Two additional practices will be added by September - Dr. Tiongson (Fargo) and Dr. Shelton (Grand Forks). A meeting with Dr. Oksa, from Dickson, has been set up in June, to determine her interest in participation in the program. They are also looking for an IHS pediatrician. A Medical Home can also serve adults

with chronic health conditions and the hope is that eventually that will spread to those populations. Nationally, Medicaid has begun funding Medical Home Providers when they have gone through training and that is one of the options that will be looked at in the future. A Medical Home Index is a validated tool that measures Medical Homeness. The Index is completed every 6 months. A family perception survey is also completed every 6 months. These tools will be able to show if there is an increase in family satisfaction and a higher Medical Home Index score at the end of the 3 years. Each practice submits monthly reports. Each child served is to have an individualized care plan. The Medical Home looks at the services the child needs, not just in the physician's office, but also at the community level. Overall, Medical Home is chronic disease management that adds quality assurance. Kora expressed her appreciation to Dr. Quanrud and Dr. Carver along with ND Family Voices, Children's Special Health Services and the Department of Health – Dr. Dwelle for their support of NDIS. Dr. Carver believes that the biggest benefit will be the coordination of care in the long run and having the care plan in place that the family can take with them when they see the specialist.

PROVIDER QUALIFICATIONS

Melissa gave an update on the specialist list. The requirements state that the physician is to be certified at the time of the enrollment. A follow-up review is conducted to make sure they are still board certified, although they are not removed from the list if they are no longer certified. In years past, there have been a few physicians who have been in their practice for quite a while and have decided to not renew their certification. In regards to the CSHS specialist list, there are only about 5 physicians who have not recertified and there are still some who have not responded. There is also a problem with physicians who are qualified, but choose not to accept Medicaid reimbursement; therefore, CSHS cannot reimburse them either as it also uses the Medicaid payment system. In return families are not able to access the care that they need unless they pay for the service on their own.

Dr. Connell asked for advice on the board certification status of the physicians who sit on the CSHS Medical Advisory Council. Dr. Wink made the motion to keep this as a minimum requirement. Dr. Klava seconded the motion and all were in favor.

Dr. Connell brought up the situation of a family practice physician that is working in a specialty area (orthopedics) and if he is qualified to provide orthopedic care. Dr. Kemp recommended that if the provider can document their credentials, they should be approved. Dr. Connell asked if this type of situation should be a case-by-case basis and if the physician can prove they have the credentials to work in a specialty are then they would be eligible for reimbursement. All were in favor.

PROGRAMMATIC UPDATES

Clinic Services-

Tammy shared the request for proposal process; it is one of the ways that CSHS gets at the community based service delivery for clinics, family support and care coordination. The requests that were received totaled about \$70,000 more than the previous biennium. CSHS is trying to figure out a way to fund the proposals that were received. A few of the providers will be asked to reduce their budget and we are trying very hard to fund the autism clinic. A lot of the same services were applied for with the addition of the autism clinic which was the only new area. CSHS typically funds clinics, family support services, Medical Home and community based coordination.

Dr. Connell asked if anyone had any suggestions regarding any additional multidisciplinary or specialty clinics that might be needed to help aid the management of complex pediatric health conditions. Dr. Kerbeshian would like to consider Fetal Alcohol Syndrome, particularly in the Native American populations in the state.

CSHS staff participated in an outside review of our multidisciplinary clinic services. The review was conducted by staff from the Utah Children with Special Health Care Needs program - ULEND project. The review provided discussion regarding the amount of quality assurance data that CSHS is collecting. It was recommended that the data collection only occur every two years since the data shows that families are very satisfied with the services. CSHS has decided to decrease the frequency of family satisfaction phone surveys to every two years, but has opted to continue to monitor the efficiency measures on a yearly basis.

ULEND staff also discussed the possibility of contracting for services that are offered at the CSHS administered Cleft Lip and Palate clinics instead of paying provider an honorarium. It was also suggested that Children's Special Health Services consider volunteer providers and giving the providers the opportunity to take a higher rate of tax deduction for their volunteer hours.

Family Advisory Council report

Evelyn Klimpel, Family Advisory Council member, was born and raised on the Fort Berthold reservation. Her youngest son, who is now a junior in High School, was born with Collier's Disease which was not diagnosed until age 2 and since then he has had numerous surgeries. She is very appreciative of all the material and new information provided by Tammy from the Family Advisory Council meetings and is very happy to have the ability to provide family input. She is also a member of the Family Voices Board of Directors. She did ask the other Family Advisory Members if there was anything they would like to share. They did mention that they were excited about the Medical Home project and all the great things it has to offer. It was also mentioned that they would all like to see the percentage of poverty raised to 200% and finally they were happy to hear about the new autism state work group.

CLOSING REMARKS/WRAP-UP

Five physicians have terms that will be expiring this year. They include: Drs. Quanrud, Klava, Sommers, Kerbeshian, and Fiechtner.

Drs. Quanrud, Klava and Fiechtner have agreed to another term. Dr. Sommers has declined, but had asked that Dr. Warford fill his position. Dr. Warford did agree to serve as a Medical Advisory Member.

Dr. Kerbeshian will be retiring this year so he will not renew his membership, but did suggest recruiting a younger psychologist to replace him.

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