



## MEDICAL ADVISORY COUNCIL MEETING MINUTES

### CHILDREN'S SPECIAL HEALTH SERVICES

May 21, 2005

**Present from the Department of Human Services:** Dave Zentner, Director, Medical Services, Department of Human Services.

**Present from Children's Special Health Services (CSHS):** Tamara Gallup-Millner, Unit Director; Robert M. Wentz, MD, Medical Director; Terry Bohn, 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; Terry Dwelle, MD (State Health Officer); Alan Kenien, MD; Jacob Kerbeshian, MD; William Klava, MD; Myra Quanrud, MD; Kerstin Sobus, MD.

**Absent:** Marcus Fiechtner, MD; Amy Oksa, MD; Dennis Sommers, DDS; Bruce Levi, North Dakota Medical Association; Joanne Luger, DDS.

**Guests:** Donene Feist, Family Advisory Council member.

#### **WELCOME & INTRODUCTIONS**

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

#### **DEPARTMENT OF HUMAN SERVICES (DHS) OPENING REMARKS**

Dave Zentner, Director of Medical Services, welcomed everyone and thanked them for providing CSHS with the necessary physician input to operate the program.

The Legislature did not make any changes to the CSHS budget so the unit will be able to continue current programs. Also of note is a study related to special needs children, HCR 3054. It is a good opportunity for everyone in the state to provide input. CSHS can be contacted for more information regarding interim legislative committee meetings and what the legislature plans to address through the study.

Dave stated the state's federal match for Medicaid is dropping. The state put in \$36 million in general funds, which will enable Medicaid to continue with the current level of services. The legislature also provided an across the board increase for all providers of 2.65% per year. This is different than in the past; this was the first time the legislature tried to equalize the process for all providers.

Medicaid will be getting a new computer system. The present system is about 27 years old. It will take Medicaid two to two and one half years to complete and will cost about \$30 million, 90% of which is

from federal funds. It will do things for Medicaid and for providers that the current system presently cannot do.

The other area that the legislature put emphasis on during the past session was disease management. The legislature provided Medicaid with a little over \$700,000 to implement a program that provides targeted case management for high cost cases, but also looks at disease states where there are protocols that can make some difference like asthma, diabetes, etc.

Dave reviewed Medicaid's budget. For Medicaid's regular programs including SCHIP, Medicaid received \$397 million. The Department received \$394 million for long-term care, which includes personal care and some other state programs. The development disabilities budget is about \$200,000. The overall total is about a billion dollars over a two-year period, which in North Dakota is a fair amount of money and again about 34% of that is state dollars. The rest is federal money.

Legislative Bills that may be of interest to the council:

- HB 1206 - Establishes a process for providers to appeal Medicaid decisions. When there is an appeal, someone at the Department who is not connected with the original decision will take a look at the request. If the service is still denied, the legal division would review. The next step would be to send it to the district court. HB 1206 gives providers an opportunity, if they feel the Department has denied something inappropriately, a different option than having the recipient make the appeal.
- HB 1459 - Establishes a drug-monitoring program where drugs that are subject to substance abuse would be in a statewide monitoring process, which physicians and others can use to ensure that proper prescription steps are taken. A task force is forming to address the issue, which includes physicians.
- HB 2395 - The Russell Silver Syndrome bill will be discussed later.

Dave announced he will be retiring effective August 5, 2005. He has been with the Department for 27 years and served 12 years as the Medical Services Division Director.

**CHILDREN'S SPECIAL HEALTH SERVICES (CSHS) UNIT OVERVIEW**

**Administration:** Tammy Gallup-Millner provided an overview of the CSHS unit. Children's Special Health Services is funded primarily through the Maternal and Child Health block grant (Title V), which operates as a federal-state partnership to improve the health of all mothers and children in the state, including the children with special health care needs population. In North Dakota, Title V funding is divided between the Health Department and the Department of Human Services. The special health care needs funding comes to the Department of Human Services and the portion for mothers and well children goes to the Health Department.

CSHS focuses on two primary missions: Direct service and Systems development. CSHS continues to operate with eight staff. Dr. Wentz is very appreciated in his work as Medical Director and has agreed to continue during the next biennium. Over the last few years, Title V funding has been flat so the unit will continue to operate on a \$1.8 million budget which includes a State Systems Development Initiatives grant that helps address data issues for the MCH population. The only change in the biennial

budget is a general fund appropriation for Russell Silver Syndrome of \$150,000. Most of the unit's funds go to salary and grant lines. Grants fund claims payment, the metabolic food program, contracts, and the Russell Silver Syndrome program. Last year CSHS served close to 1400 kids through direct service programs.

**Specialty Care Program:** The caseload for diagnostic and treatment services runs a little over 300. CSHS has noted an increase in pharmacy, more medical management rather than hospitalization costs. Financial eligibility remains at 185% of poverty. CSHS provided about \$200,000 in claims payment. Conditions CSHS paid the most for were diabetes, cleft lip and palate, hearing loss, heart conditions, handicapping malocclusion, congenital urinary tract anomalies, asthma, and seizure disorders. Ninety-four percent of children CSHS serves have a primary source of insurance coverage. A couple of years ago, CSHS instituted a \$20,000 per year coverage limit. This year, there has been one instance where a child who had a seizure disorder met the limit.

**Multidisciplinary Clinic Program:** About 80% of the 1400 kids served by CSHS are seen through the multidisciplinary clinic program. State staff continue to manage the cardiac program, scoliosis, and cleft clinics with the help of providers at the local level. Service contracts that will be funded for the next biennium are currently being reviewed. CSHS continues to have very high family satisfaction in this area. Families agree that clinic services help them manage their child's condition.

The biggest challenge this year was finding providers to staff the scoliosis clinics that Dr. Haasbeek had previously covered. General orthopedists are not comfortable in providing the follow-up. Clinics were held in Grand Forks, staffed by Dr. Johnson, and in Bismarck and Minot, staffed by Dr. Moore. Out-of-state referrals have sometimes been necessary for bracing or surgery.

There was no clinic in Fargo; however, Dr. Haasbeek will be returning in September. Dr. Klava indicated Dr. Haasbeek is planning to spend half his time for orthopedic spine surgeries but will likely not be doing outreach clinics in future.

**Care Coordination Program:** Ms. Gallup-Millner stated the care coordination program provides case management services through public health nurses and county social services. CSHS has conducted site visits to encourage county CSHS workers and eligibility staff to talk with each other. A lot of families come in the Medicaid door. If they are not eligible, they don't always get referred to other programs that may help. CSHS is planning to revise the county case management program, reducing the paperwork burden for county workers while assuring appropriate coordination services for families. On the public health side, public health nurses are tending to serve kids that are medically fragile or that have multiple health conditions. They are also serving families that have more than one child with a special health care need as the burden of care is greater. Public health does a much more intense level of case management and support. Over the year, technical assistance has been required from the state office. Families are struggling with access to dental services, insurance and billing issues. About 75% of the care coordination families served by public health are eligible for medical assistance. One of CSHS long-term goals is to expand the care coordination program to other areas of the state.

**Metabolic Food Program:** CSHS provides formula and low protein food to individuals with PKU and MSUD. Currently 21, clients are served through the metabolic food program.

Approval of Minutes

**Dr. Quanrud moved to approve the minutes. Dr. Dwelle seconded the motion and all were in favor. The minutes were approved.**

#### Certification/Re-Certification

Recently a review of all the CSHS provider files was completed. Leann Bayman informed the Council that CSHS maintains a list of providers who have been approved to provide services for children served by CSHS. A spreadsheet documenting the provider's certification was developed with each providers' information. When the certification has expired, the recertification will be researched on the specialty's website or requested by letter from the provider. There are a few specialties that are hard to find. Currently the spreadsheet is about 90% complete. The North Dakota licensure will also be checked twice a year.

#### Medical Eligibility

##### Coverage of a ketogenic diet for individuals with seizure disorder

There was some discussion last year on the ketogenic diet. Sometimes a special tube feeding is used in the younger child or a child that is severely impaired to try to maintain the ketogenic diet. It's an old treatment but there is still a role for it.

Dr. Sobus stated they are currently using it for kids who have not responded to a multi-drug regimen, most of whom are tube fed. Coverage of the ketogenic diet was recommended if the child had failed medication because it can be very effective.

Sue asked with the ketogenic diet is that just a premixed formula already developed or is it adding regular food products to achieve the diet.

Dr. Quanrud stated if the kid is oral and can handle regular food that's where it goes. Specialty formulas and a dietician consult are things insurance very often will not cover.

Sue asked what a dietician consult includes?

Dr. Sobus stated the kids are usually seeing Cathy Breeden or a highly qualified dietician that counsels them on how to do this diet because you can't mix other medications and other items can't be mixed with it.

Dr. Wentz stated it sounded like there is a consensus about covering the ketogenic diet for a child with seizures where they have been on multiple medications, particularly if it is a tube feeding.

Dr. Klava stated again CSHS would cover what otherwise would not be covered.

Dr. Carver thought it should be limited to the child who requires tube feedings.

Dr. Quanrud asked are we talking about tube feeders or specialized formula because cream goes down a tube very nicely.

Dr. Betting stated they like to do everything as a team in Minneapolis.

Dr. Klava stated if testing is required prior to surgery he could see where they would want to have all of their data in one place and do everything consistently because obviously they are doing study work as well.

Dr. Betting asked the question if there are dieticians here, is there any reason the ketogenic diet couldn't be done here as an inpatient?

Dr. Betting stated he has had two requests this year to do the diet as an inpatient at MINCEP. They say it is so complicated and they have to watch these kids carefully.

Dr. Sobus stated it depends on the size of the child and how severe the seizures are.

Dr. Betting said as far as instituting the diet, food is withheld for 24-48 hours and then the diet is started. Is there any reason why the diet can't be started at home, especially for those children on a tube feeding who are not mobile and cannot go to the kitchen and grab a snack.

Dr. Sobus stated a pediatric neurologist needs to approve the diet.

Dr. Quanrud stated it would have to be on a case-by-case basis but for the average ketogenic diet, it should be able to be started at home within state.

Ms. Millner stated she would like clarification on special formula or just kids that need to be tube fed?

Dr. Quanrud stated cover the special formula, not the foods that go into the ketogenic diet.

Dr. Sobus stated one needs to be careful if the child is at MINCEP as they are there for a reason.

Ms. Millner asked how would you know when it would be appropriate to refer.

Dr. Kenien stated if the pediatric neurologist that is evaluating the child feels the child should be evaluated in another center, then that would be the opinion he would take.

Dr. Kenien stated he knows Dr. Reggin referred several patients to MINCEP because he did feel he was doing all he could for the child.

Dr. Quanrud stated one of her patients went to Mayo. Mayo recommended the ketogenic diet. The patient came back, saw Dr. Reggin and started the diet.

Dr. Sobus stated Dr. Siriwan Kriengkrairut has referred people to MINCEP and Dr. Guina is currently following people and has referred them to MINCEP. Dr. Sobus stated you can't bring people back from MINCEP; there are reasons why they are there.

Dr. Quanrud stated having the pediatric neurologist recommendation would be a good idea.

Dr. Cook stated she has referred patients to MINCEP when they have been impossible to control. In the last few cases referred there, implementing their recommendations has been possible locally and it has

resulted in very dramatic improvements in the kids and cut the costs of their care way down. It's a resource that would be nice to consider pretty readily available to us as long as neurologists agree.

Dr. Wentz stated there is a consensus on the ketogenic diet.

#### Neuropsychological services

Dr. Sobus states as far as neuropsychological services, it is done to assist with school planning. Most of these kids have insurance that covers it, but the school may be responsible for coverage in some cases.

CSHS staff would like to know what qualifications are needed to be able to provide neuropsychological services.

Ms. Burns stated there are very few board certified neuropsychologists in the state.

Dr. Kerbeshian stated there are a number of clinical psychologists who say they do neuropsychological testing.

Sue asked if there is a difference between who can do the testing and who can do counseling after the child has been tested. Should they have the same qualifications?

Dr. Kerbeshian stated that neuropsychologists would not typically be providing psychological counseling. They would provide interventions and consultation to other service providers and are more aligned with neurologists and educators.

Dr. Klava stated the general psychologists don't actually even do the testing themselves. Often it's done by a technician but the interpretation and the direction as to what one would do as a result of the testing is what's important. There was a concern that if CSHS requires physicians that provide services to CSHS be board certified, why would neuropsychologists not be required to be board certified as well.

Sue asked Dr. Kerbeshian about a qualified person doing the testing.

Dr. Kerbeshian stated there is usually a postdoctoral training program in neuropsychology.

Dr. Sobus stated you usually need a person who has had post doctorate training.

Ms. Millner asked if they need to be board certified or not. North Dakota does not have a lot of folks that are board certified.

Dr. Kerbeshian stated their certification would not be the same certification as medical board certification. He requested CSHS contact the American Psychological Association and ask them what is their definition for a neuropsychologist, what are the training requirements, and do they have any certification.

Dr. Sobus stated neuropsychology testing is done before surgery to know what the child's cognitive function is before doing surgery, and then it is done post surgery to know if the child has any deficits after surgery.

Dr. Cook stated she checked the web for the American Board of Child Psychology and they do have a certification process claimed under psychology. There is board certification available for clinical

neuropsychology.

Dr. Sobus stated she did not think anyone in the state was board certified.

It was stated there are a few in North Dakota that do have their board certification.

Dr. Klava stated he has a concern there are a lot of people who call themselves neuropsychologists who are doing neuropsychological testing that are really questionable with their credentials.

Dr. Kerbeshian asked how many of those neuropsychologists are pediatric neuropsychologists.

Dr. Wentz indicated CSHS will likely require the neuropsychologist be board certified.

Coverage of surgery for individuals with a seizure disorder

CSHS has had one request this year. Is there still a feeling that CSHS should not get into surgery for individuals with seizure disorder because of the \$20,000 cap.

Dr. Betting stated good results are achieved.

Dr. Wentz stated he has mixed feelings about it. It can really reduce the cost of care if successful.

Dr. Wentz stated it has become much more common so he would be inclined to say CSHS ought to cover it, if that is the way families want to spend their \$20,000.

Dr. Kenien stated he had a child who had a resection of the corpus callosum and is still having terrible seizures but now the recommendation from MINCEP is to have one of the hemispheres removed, a hemispherectomy.

Dr. Sobus stated they have kids all the time having that surgery. She has no problem covering surgery if it is done right.

Dr. Kenien stated the cost would be at least \$200,000.

Dr. Klava stated they did hemispherectomies 25 years ago and then everybody stopped doing them and now it is being reinvented.

Ms. Millner stated the majority of the children that CSHS serves do have a primary source of insurance and CSHS does the gap filling. The \$20,000 can make a difference for a family.

Dr. Kerbeshian mentioned another thing to talk about would be the likelihood of a positive outcome and the cognitive assessment. It may not be something that is predictable based on surgery outcome. For some patients there would be an estimate of probability of outcome, but is that something one could factor into the equation?

Dr. Klava stated he hoped we are talking about intractable condition that has not responded to all other means of conventional care first.

Dr. Kenien asked what happens to a person who is on Medical Assistance who goes out of state to have this surgery done and it costs \$200,000. Who gets stuck with the bill, if CSHS only covers \$20,000?

Mr. Zentner stated if they are Medicaid eligible, Medicaid pays the full bill. If they are eligible for only CSHS then the family would be responsible and, of course, the facility is going to have a very difficult time. The facility will know up front that there is a substantial amount of dollars that probably are not going to be covered, which will be a write off for them. The facility will have to decide whether they are going to do it or not.

Sue stated families are aware of the \$20,000 limit. If someone is having a surgery and especially if they don't have insurance, CSHS is careful in notifying that facility that they only have the \$20,000 of coverage so they are going into it aware as well.

Sue stated CSHS excludes surgery for the condition of seizures. Surgery is an eligible service for the other conditions. Should the exclusion of surgery be removed from this condition? Surgery would only be approved if the specialist recommended it.

Dr. Wentz asked the Council their preference.

Dr. Quanrud stated it is reasonable to do.

Dr. Klava stated that's what the cap is for. If that is how families want to use what is available to them.

#### Metabolic Conditions

The state is working to add cystic fibrosis to newborn metabolic screening. A pilot will be started this summer. The screening cost will increase by \$8.00. CSHS currently covers cystic fibrosis.

Ms. Millner stated CSHS knows one woman with PKU who had a successful pregnancy.

#### MPS1

Dr. Wentz stated the group was polled and the MPS1 condition was added. The specific family involved currently has some other coverage so they haven't had to utilize the program. One of the issues that came up was should the program cover the enzyme replacement therapy and bone marrow transplant that are used as part of the therapy. Dr. Sobus has raised the issue of treatment efficacy. Dr. Wentz received some information from Genzyme, the pharmaceutical corporation that produces not only the enzyme being used to treat MPS but also the Fabrizyme that he is on. The enzyme is very expensive for both conditions. All enzyme replacement therapies are extremely expensive. He commented that this particular child is now on home therapy, actually getting her infusions weekly at home. The question was again on the \$20,000 limit. Should the family be allowed to use it to apply towards bone marrow transplant or enzyme replacement therapy? If the enzyme is costing \$6,000 to \$8,000 every two weeks, the \$20,000 would not go far for that and certainly would not go far for a bone marrow transplant. Should the family be allowed to use this option? Enzyme replacement therapy is going to become more and more available until there are more specific genetic cures.

Dr. Dwelle stated with the \$20,000 limit, this would give the parents more options.

Dr. Wentz stated in general the enzyme replacement therapy seems to be pretty effective. Some of the changes are pretty remarkable. The big issue in terms of MPS and some of the other conditions is whether or not the enzyme gets into the central nervous system. For the child that CSHS is involved with in the state, the mother does not want to go through the bone marrow transplant. On the other

hand, she's needing to watch her child's development very carefully. Some of the geneticists are saying once changes start to be seen in the child's development, you have waited too long. There is a lot of pressure for MPS1 children to have a bone marrow transplant.

Dr. Wentz asked if there are any strong objections in letting the family make the decision. There were no objections.

### Condition Grid

A condition grid listing each CSHS eligible condition has been developed. Dr. Wentz went through each of the conditions and applied the listed criteria to assign a "score". CSHS is trying to develop a tool the Medical Advisory Council and/or Medical Director can use to determine if a condition should be added as an eligible condition.

There are several conditions that have come up, some of which have been discussed previously.

- Muscular Dystrophy – Last year Dr. Sobus pointed out there may be 75 different conditions, many of which are metabolic disorders including mitochondrial. Should that term be used, as it would open up a huge category of conditions.

Ms. Burns stated families have said the Muscular Dystrophy Association doesn't help with everything they need.

Dr. Sobus agreed that the Muscular Dystrophy Association does not cover everything.

Dr. Sobus stated families do get to go to a clinic that is covered.

Dr. Klava stated the Association pays for travel expenses, prosthetics, and power equipment. They generally cover over and above what their own insurance doesn't pay for and also try to get funds from other sources.

It was stated families may need help in between the muscular dystrophy clinics.

- Eosinophilic Gastroenteritis - CSHS has had a child with some severe problems with eosinophilic gastroenteritis where the providers are having difficulty controlling his condition. The providers are talking about going to the National Institute of Health to see if there is anything that can be done.

With eosinophilic gastroenteritis, there is a question if it is an allergy or not. Dr. Wentz reviewed literature that stated 50% of patients have a history of atopy (hayfever, asthma, food allergy). It is uncertain what the triggers are that stimulate this inflammatory response in this particular child that CSHS has been involved with. This is a child that is atopic and has some significant food allergies but also has this chronic gastrointestinal problem, which is quite disabling.

- Mitochondrial disorders - Some of the conditions that are on the CSHS list are considered mitochondrial disorders. We have come to realize a number of other conditions are actually mitochondrial disorders, at least 40 different kinds. The incidence is about 1 in 4,000 individuals also have some type of mitochondrial disorder. There is some question whether

they are treatable or not. In more recent years, there has been some success in treating them with enzymes or antioxidants.

Dr. Sobus stated she would put mitochondrial on the list because the muscular dystrophy is not going to pick these kids up. Most of them are spastic quadriplegic or they are spastic biplegic.

Dr. Sobus stated she would not add muscular dystrophy because the Muscular Dystrophy Association is going to pickup the general list. Most of the mitochondrial children are not going to get picked up under muscular dystrophy.

There was discussion that there are a lot of conditions that fall under the Muscular Dystrophy Association coverage area that are also mitochondrial disorders. Mitochondrial disorder may be too broad of a term.

Dr. Sobus stated it is a new group of disorders that has been recognized in the last 10 years. They are continuing to come up with a classification. The number of diagnoses is rapidly increasing. Most of these kids fall under the rehab category as spastic quad kids or hypotonic kids and fall under the CSHS category. They have feeding disorders, positioning disorders, bracing needs, and are going to have orthopedic surgery needs.

Dr. Cook asked if Medicaid and CSHS are covering the cost of mitochondrial co-factor therapy because many of the medications are available over the counter and are therefore not covered and the families have difficulty paying for them. She thinks it is more of an issue of Medicaid covering these pharmaceutical use agents right now. Many states are already doing it rather than having it be under Children's Special Health Services

Mr. Zentner stated it is possible for Medicaid to cover over-the-counter drugs and in fact Medicaid does cover certain types of analgesics. It might be something Medicaid would want to look at. Medicaid does have a committee that looks at issues like that. If there is some interest in supplying Medicaid with information regarding efficacy, etc. Medicaid would take a look at that.

Should CSHS continue to develop this infinitely long list of conditions or should the unit approve a condition that meets a set of criteria that is chronic, complex, serious, and requires interventions. Does CSHS allow the Medical Director to say this meets the criteria or does the list get longer and longer? Dr. Wentz finds it really difficult and offensive to be denying care to kids that need services while the kind of money is being spent on war and other things. He is much more inclined to try and convince the legislature that there are kids that have complex disorders where the family needs some help and the current medical system does not address these kinds of problems.

Dr. Kerbeshian stated we are all over the board with inconsistencies. It makes it difficult to graph them that way and it's difficult to make decisions. We are straddling in different levels of organization as these conditions are being looked at. Then we get back to years ago when we were discussing the issue whether a determination should be based on function rather than diagnosis at whatever level. We are digging ourselves in deeper in terms of this discussion because we are adding another level of chronic complexity that's going to make it very difficult to decide. One thing you might want to do is get back to that basic issue of do we want to maintain a degree of consistency. Someone is going to have to make rational decisions or struggle with what we have. If you want to have something that is consistent at the same level, what should that level be?

Dr. Wentz stated CSHS struggles with the syndrome issue.

CSHS is not comfortable with the condition list but a better way of establishing medical eligibility has not been established. CSHS is rationing care. Is the condition list an appropriate way to ration care for the children in North Dakota or not?

Dr. Kerbeshian suggested changing the graph from horizontal access to vertical access, turn it the other way. The framework is here in which eligibility could be judged as a way of identifying the severity.

Dr. Dwelle stated he agrees with the list on the left and the vertical list. It actually comes down to judgment. It can be argued that this does or this doesn't make sense. If those decisions are being made, can't the authority and responsibility be given to someone to use those criteria and make a judgment in each case?

Ms. Millner stated there was discussion on using a scale of 0 to 20. CSHS would look at conditions that rank 15-20 and indicate those are the children that should definitely be served in North Dakota. CSHS would probably have to do two parallel methods for a while to determine the impact. CSHS is trying to get a method that is better than the condition list. Should we start attempting to do that or not?

Dr. Kerbeshian stated it could be a sliding scale based on the availability of funds. CSHS could then give a degree of inequity that would be equal. Once a child is in the program, they go all the way. They get the best outcome they can get. Their life may be better than the person that fell a little below that scale.

Ms. Millner asked for a recommendation.

Dr. Kerbeshian stated while continuing to do business as usual, consider doing a pilot plan over the next year by applying the model of letting the primary determine the service delivery to see what the difference would be in terms of eligibility and costs and change the graph to a vertical access.

Dr. Wentz asked if CSHS received an application from a family and the condition was not on the list, would CSHS then try to get that family to share with us what their costs are.

Dr. Kerbeshian stated he would start with the correct list. How many would have been included and how many would have been excluded?

Dr. Wentz stated he can't answer what the fiscal impact would be if we opened this up because there have been surprises both ways. Celiac disorders were added and we have not had an application. Most families have some type of health insurance coverage and CSHS is doing more of the gap filling. What is the impact if we open things up? Some of these conditions being talked about are extremely rare but some are extremely expensive.

Dr. Wentz stated usually an application is not received unless someone has heard that the program may cover this condition.

Ms. Burns stated the four on the list are the four that have been denied.

Ms. Feist stated she can understand the sliding scale but what happens if the family has no insurance and they have a high income need.

Dr. Kerbeshian stated the sliding scale would be used for eligibility and if someone was eligible, they would receive full service on the access of payment.

Dr. Quanrud asked the last two years could be looked at to see how things would plot out.

Dr. Wentz stated these are areas where there have denials. There is a concern about expanding the financial impact of the program and how to determine that impact if some of these cases had been approved.

There are many questions not known.

Dr. Dwelle asked if CSHS sees their projected budget at any particular time.

Ms. Millner stated it would be difficult because there is a lag time with claims.

Dr. Dwelle stated if CSHS knew their projection, they could at any particular time say they are under the projection and therefore, could use the criteria to make a decision on a child. If CSHS was over the projection then it goes back to CSHS can't consider this child. This would be a way of testing it for a while.

Dr. Wentz stated what would happen is as it gets close to the end of the biennium CSHS would start cranking it out.

Dr. Dwelle asked if CSHS has ever used up all the funds or does CSHS have an average of what is left.

Ms. Millner stated CSHS usually has some left but the problem is you don't know what kids have insurance or not, you don't know the high cost kids. A little room is left for that so CSHS does not go over.

Dr. Dwelle asked is there a way historically that CSHS can get a handle on how much wiggle room Dr. Wentz would have for new conditions coming in that are not on the list and still have some wiggle room left?

Mr. Zentner stated CSHS funding is not like Medicaid where the federal government match is 65%.

With CSHS, there are fixed amount of dollars that can be matched. He does have the opportunity through the programs to move money around but still has to be able to match what's out there for the federal government so that kind of limits what he can do on that program.

Ms Millner asked overall how everyone felt about the criteria and the grid, and stated she would like everyone to complete and turn in the back page.

Dr. Klava stated it was easy to apply to muscular dystrophy. It was more difficult to apply to mitochondrial, as there are many types of mitochondrial disorders.

Ms. Feist stated she has concerns for those families that may fall 1 or 2 points below the scale and may have significant needs and where some families may have more income.

Dr. Wentz stated the income eligibility would still be there. This is only for the eligibility of the condition.

Dr. Dwelle stated a little bit more option rather than sticking to a grid would be given. It is actually giving a little more freedom if there are additional projected funds or if the medical director is actually making a decision to add a condition, it is a way of testing to see whether or not there would be a run on this, whether a whole group of conditions are being missed.

Dr. Kerbeshian stated he thinks we are talking about changing our focus from disease to illness.

Dr. Klava stated we are talking about burden of illness, how to help manage burden of illness for families. Are there criteria that helps look at that objectively?

Dr. Wentz proposed that CSHS carry out a study for the next year. If applications are received for conditions that are not covered, there would be three people, including himself and two other members of this body or another member of this body or say a pediatric neurologist or some specialist in the area to help make the decision on eligibility. CSHS would keep track of the cost involved and bring it back next year .

Dr. Quanrud stated it might be good to screen everyone that applies.

#### Covered Services

One issue that has come up is vision therapy for kids with strabismus. There is a neuro-optometrist that is doing evaluations on kids with strabismus. The practitioner is proposing up to 70 treatments that are fairly expensive. Dr. Wentz contacted Dr. Gail Sommers, a pediatric ophthalmologist at University of Minnesota, to request her opinion on vision therapy. Her response was provided in the packet of materials for the meeting. Her advice was to limit coverage to convergence insufficiency type of exotropia, and then allow up to a maximum of six visits.

Ms. Burns stated that currently, CSHS covers one visit. Medicaid covers some of them.

Dr. Kenien states he does not think it should be covered at all.

It was the consensus to not cover vision therapy.

### Allergy Shots

Last year there was discussion on not covering allergy medication or triggers for asthma. This becomes hard to explain since CSHS covers allergy shots. When a child receives allergy shots, the shots may cause nasal symptoms or a sinusitis. The medications to treat those symptoms would not be covered. CSHS only covers asthma medications. If CSHS does not pay for asthma triggers, should they be paying for allergy shots? If CSHS does pay for allergy shots, should they pay for the medications needed to treat the related symptoms of the shot?

Dr. Wentz stated if a child has asthma and they have allergic rhinitis, when that flares up sinusitis can be a trigger for their asthma and then we don't pay for treatment of sinusitis.

Dr. Sobus stated this can run up claims.

Dr. Dwelle asked what is considered moderate. Is it starting at step 2, step 3 and step 4 or is it step 3 and 4?

Dr. Wentz stated step 3 and 4 is how CSHS tries to define it. CSHS runs into a problem where reports do not make a specific category diagnosis but the child is on controller medications. It is sometimes really hard to know what category they are in so CSHS goes by what medications they are using.

Dr. Sobus stated it comes down to the issue of what kids do we want to serve and how much money do you want to spend.

Dr. Wentz asked whether Xolair should be covered?

Dr. Kerbeshian stated CSHS should pay for the standard treatment of asthma.

Others stated BCBS is not covering over the counter medications.

Mr. Zentner stated Medicaid is covering Claritin over the counter.

Dr. Kenien stated there is a generic Claritin that is identical that is half the price.

Dr. Quanrud stated she would cut it off with the antibiotics because if you treat pneumonia in a child with a cardiac condition, they might end up in the hospital. A big door would be opened.

Dr. Cook stated for asthma medications they have had absolutely no difficulty in getting anyone who doesn't have proper coverage for their asthma medications under the patient assistance program.

It was stated the medications are expensive. Do we cover the pneumonia that triggers the asthma? Do we cover the inpatient hospitalization for pneumonia that is triggering the asthma? Do we cover the antibiotic for the sinusitis. We don't cover sinusitis. It was stated there have been many times when a child has a viral infection.

Dr. Wentz stated there are times when he has denied things because it was clearly defined. However, the other day he had a classic case of a child that had an asthma episode that was triggered by a viral illness that the physician diagnosed as bronchitis and treated it with antibiotics. He felt CSHS should cover it as an asthma episode.

It was stated allergy shots may flare up a child's allergies causing triggers in asthma.

Dr. Wentz stated CSHS is going to end up having to say this was an upper respiratory infection that was treated with antibiotics and coverage can't be justified.

Ms. Dockter stated CSHS is paying for allergy testing and allergy shots, should we be paying for allergies or should we not be paying for them?

Dr. Quanrud asked would this be only for kids with asthma?

Ms Burns asked do you only approve medications to those getting the shots?

Dr. Wentz stated the antihistamines are more available over the counter but then you get into the nasal steroids that aren't over the counter. They can be fairly expensive.

Dr. Kerbeshian suggested CSHS pay for the shots and leave it at that.

Dr. Wentz relayed that in pediatrics, there are medications that are not FDA approved for various conditions.

Dr. Klava stated we still have to go by what is the standard of care. There are many things that are not FDA approved that are still considered a standard of care.

Dr. Dwelle stated it might be better to list step 2, 3, and 4 rather than saying moderate to severe. The reason for including step 2 is it's the start of continuous medication.

Dr. Wentz agreed about adding the steps.

#### Pneumovests

Dr. Wentz stated CSHS had a family inquire about pneumovests for their child with cystic fibrosis.

Mr. Zentner stated Medicaid covers the pneumovests.

Ms. Burns asked if the vest is now considered the standard of care for kids with cystic fibrosis?

Dr. Sobus stated it is known the kids with cystic fibrosis will live longer with it. It is the standard of care if someone has cystic fibrosis. There is a national study going on now for kids with cerebral palsy and related disorders. That data will probably be out this fall.

Children with cystic fibrosis use the vest up to two times a day depending on the severity. For kids on the national cerebral palsy study, it is two times per day up to 4-5 times a day if they have a respiratory infection. Children with certain types of muscular dystrophy may have a vest if they are in the pilot study program.

Dr. Quanrud stated she has kids with cerebral palsy that are on the vest and have received good results.

Dr. Carver stated he has one kid with cystic fibrosis and one kid with cerebral palsy who use the vest.

Ms. Millner asked whether the vest is recommended for conditions in addition to cystic fibrosis.

Dr. Sobus stated they are quite beneficial and stated she could get CSHS some data.

Dr. Sobus stated the machine is more portable than it was years ago and the vests come in different sizes.

#### Nurse Practitioners

Dr. Wentz stated CSHS has had an issue come up regarding reimbursement of nurse practitioners and physician assistants. For example, with scoliosis sometimes the nurse practitioner does the initial assessment before the child is seen by the specialist. CSHS would like to approve this service when it is a Nurse Practitioner or Physician Assistant.

Ms. Burns stated it is usually the nurse practitioner or physician assistant that work with the specialist.

Dr. Klava asked if nurse practitioners are required to be directly supervised by the specialist?

Dr. Klava stated if they working in a specialty area, the care should be directly supervised.

It was stated there are more nurse practitioners and physician assistants who practice independently in the rural areas.

Sue stated CSHS requires them to see the specialist and the specialist needs to delegate care back to the primary care provider for CSHS to cover.

#### Infant Formula

Dr. Wentz stated CSHS receives requests for new and different kinds of special formulas which are showing up for various conditions.

Ms. Burns stated the requests are for disease specific conditions. The biggest issue is that during the first year of life, both BCBS and Medicaid say they don't pay for infant formula as it is a routine part of infant care. CSHS would like to know if specialized formulas should be covered.

Dr. Kenien asked if WIC pays for any of that.

Ms. Burns stated they can be referred to WIC, but WIC doesn't always cover everything they need for the month either.

Dr. Klava asked how do the private insurers get around paying for something if it is disease specific for a condition?

Ms. Burns stated they don't cover anything the first 12 months as all infants need formula the first year.

Mr. Zentner stated Medicaid is struggling with it. Medicaid's concern is if the door is opened up, how it would work.

Dr. Klava stated it is a medical treatment that is warranted.

Dr. Kerbeshian noted that if they are tube fed because of the child's illness, then that is medical feeding and not nutrition.

Dr. Carver stated there are infants that require the special prescription formulas like Neocate that are not tube fed.

Ms. Millner asked for a recommendation. Should CSHS cover formula regardless of whether the tube feeding is required?

Dr. Quanrud stated if it is at Wal-Mart, it is probably a standard formula.

Dr. Wentz stated maybe one of the things that should be looked at is whether it is prescription or not.

Dr. Sobus stated you get a little bit of a can of worms when you start. WIC does provide some of these. When a child gets up to 27 calories, then the child goes through it more rapidly. Do you then say sorry you are going through it more quickly so we are not going to supplement you.

It was the consensus to cover prescription formulas.

### Mental Health Services

Dr. Wentz stated CSHS continues to encounter the issue of covering mental health services for children with chronic health conditions. Should CSHS get involved in that? Children are put on antidepressants because they are feeling badly about their illness, which contributes to the depression.

Dr. Quanrud stated if you are going to open that up you should probably open up children with chronic bipolar disorder, the whole range, as they are short of services.

Dr. Wentz stated it is a little different in that these kids already have an eligible condition and are having emotional problems relating to their condition. The problem was discussed that there are not adequate mental health services available for kids in the state.

Ms. Burns stated CSHS had a child that was terminal and had depression.

It was recommended using the discretion of the Medical Director. Could also use the severity grid as a guideline.

Mr. Zentner stated it is amazing how many individuals on Medicaid have chronic conditions along with the mental health issues.

Ms. Burns asked if neuropsychological services will be limited to certain conditions.

Dr. Kerbeshian stated neuropsychological services could be helpful for kids with learning disabilities. The services can help them but the question is whether it is pertinent to the condition being treated.

### **Programmatic Updates** Needs Assessment

Mr. Bohn stated Children's Special Health Services works with Maternal and Child Health in the Health Department to conduct ongoing needs assessment activities. CSHS is in the midst of a 5-year needs assessment. The idea is to identify the most important health and service needs and those of the highest priority and then use that information to guide program decisions and policy development.

The CSHS Needs Assessment and Planning process handout depicts the process that has been used over the past year. The first step was to identify available data that could tell us about children with special health care needs in the state. There was a national survey of children with special health care needs done a couple years ago that has state level data that gave us very good information. The program conducted a survey of the families served directly in the CSHS program. CSHS also contracted for some provider surveys that were done last summer, as well as family focus groups across the states. We had a fair amount of information available to us. A planning retreat was held last October. The group reviewed the data and used that to start the prioritization process. What they wanted to look at specifically were the six national measures for kids with special needs. They wanted to be able to assess the kinds of screening and referral and follow-up that was happening, medical home status, insurance status, service system organization, transition issues for our adolescents, and family partnership and satisfaction. They wanted to be able to assess those kinds of issues as well as many others.

Essentially as a result of that retreat and some follow-up work, thirteen priority needs were identified for children with special health care needs in the state. They were categorized around four topic areas. There were some needs around health status, healthcare access, and the impact of special needs on both the child and the families and there was some service system issues as well. Plans will be developed for each of those thirteen needs over the next year and then into the future. The plan was narrowed down to three performance measures over the next five-year period. Those are to do a better job of assessing the impact of extraordinary medical needs. By that we mean a group of children that have real specific needs such as medical fragile kids. We don't understand that group of kids very well. What are their needs, what are the impacts? We hope to be able to study that. Secondly, access to specialty care seems to be an issue. We hope to be able to identify some specific kinds of activities to impact that. Thirdly being able to increase information awareness for services continues to be a need for families.

### Birth Defects

CSHS has been working with the Health Department, the March of Dimes and the School of Medicine at UND. A birth defects surveillance program has been developed for the state that is two to three years old now. That is still growing and evolving to some degree.

There are currently 45 conditions that are being monitored in the program. This is the standard that is recommended by the CDC and what most other states are monitoring. We started with a handful of conditions and tried to build around that. The second thing that has occurred is that we are starting to integrate with other programs, such as the newborn screening programs. We hope to integrate with the genetics program in the future and others to get a better picture of these children, which of those have specific birth defects as well as other issues.

A couple things we are looking into is a mechanism to be able to notify families of services available to their children. We would also like to improve our recording of data. Right now we are just collecting data from external secondary data sources. We think our data is complete. We would like to see if there is a way we can work with health care providers, clinics, hospitals, physicians to notify the program of children that they know of with this list of birth defects. Some states have legislation that

says you must report any birth defects. Others just have written agreements with healthcare facilities asking them to share data and notify the state program. There are various ways to do that. CSHS would like to know if the Medical Advisory Council thinks this is a good idea and a good way to collect data in any way that protects the privacy of the patient and their families.

Dr. Klava stated right now this is done on a voluntary basis.

Mr. Bohn stated the information we get now is identified on the birth certificate or death certificate, Medicaid claims and those served through CSHS. These are the only three ways children are being identified now.

Dr. Dwelle stated Medicaid and Blue Cross are covering about 80% of the population. How receptive is Blue Cross/Blue Shield to capturing this kind of data?

Mr. Bohn stated they have not approached them.

Dr. Dwelle relayed there are still people that will fall through the cracks but at least you might get a handle on 80% of the population.

Dr. Dwelle stated the Health Department developed something called the master patient index. Master patient index pulls in unduplicated data from the vital records of all the births and also is going to be pulling in all Department of Transportation licensure unduplicated data. When you think about that, you get multiple results and kids in unduplicated form in the state. If you could somehow link your database off that master patient index it might actually simplify your process.

### Asthma

Kora stated in September stakeholders were called together and discussed the need to have some legislation that would allow students to carry their emergency asthma meds or their anaphylaxis medications. A need was found out there. Sixty percent of the schools reported they had policies that would have allowed a child to carry those medications. Senator Gary Lee from Fargo was the lead sponsor on the bill (SB 2163). The bill passed unanimously. There are a few requirements of the bill which will go into effect August 1, 2005. The family will need to provide the school with information that indicates the student has been instructed in self-administration of emergency medication for the treatment of asthma or anaphylaxis. Documentation of the name and frequency of each medication prescribed to the student is required. They also need guidelines for the treatment of the student in the case of an asthmatic episode or anaphylaxis event.

The State Asthma Workgroup is in the process of developing a web-based training for providers to bring them up to speed on the requirements. Right now, the North Dakota State Asthma Action Plan is being used to provide the needed documentation. Dr. Dwelle is working on a North Dakota Anaphylaxis Action Plan that can be used and submitted for that documentation requirement. Dr. Aaron Gunderson covered the asthma section of the web based training. He had done a Meritcare training on Asthma and had used all the North Dakota tools that the Asthma Workgroup had come out with a couple years ago. We thank him for doing that.

A copy of the bill is attached and also a copy of what other states have done for legislation.

### First Sounds

A copy of the poster and brochure is in the packet. First Sounds began five years ago as a result of a grant to provide a hearing screening to all newborns prior to hospital discharge. About a year into the grant, the focus changed to include follow-up on referred screenings and the tracking and diagnosis of hearing loss. When this program was started, only about 39% of births were being screened for hearing loss before hospital discharge. Now, over 95% of babies are being screened. The project provided screening equipment in each hospital, a web-based tracking system, and training to the staff who conduct the hearing screen. First Sounds is having difficulty tracking a child once he or she leaves the hospital. First Sounds, which is located at Minot State University, received another grant from the Maternal and Child Health Bureau for the next three years. That grant will focus on what should occur once the child has left the hospital.

Dr. Quanrud stated the clinic has added follow-up onto the neonatal form so when the child gets to the first visit in the clinic, the newborn screening results show.

Ms. Burns stated they have been adapting the birth records for the last couple years and there will be a section on the birth record that documents the newborn screening result.

Dr. Sobus stated her nurse has been able to find data on kids she sees and the parents now know if their child had the newborn hearing screening.

Dr. Sobus stated she has not had a child that could not be rescreened.

Dr. Carver asked where the problem is that only 95% are getting screened?

Ms. Burns stated it may be a reporting issue, parents who refuse newborn screening, or home births. The Developmental Disabilities unit actually bought those regional coordinators screening equipment.

Dr. Sobus stated there is a large amount of adopted infants coming in and we need to make sure those children are screened.

#### Family Advisory Council

Mr. Bohn stated CSHS has a Family Advisory Council that is made up of nine members who are all parents of children with special needs, which has been in operation for 7-8 years. The Council meets on a quarterly basis.

Ms. Feist, a member of the Family Advisory Council, stated there have been some great things that have come from the Family Advisory Council. When family members first start on the Council, they initially look at their child's diagnosis and now they see the bigger picture. The members have become much stronger advocates. Donene attends some of the multidisciplinary clinics and meets with a lot of the families that are there. The families love the clinics a lot. They like the family support they receive and just the whole friendliness of it. Donene shared a copy of the Family Voices Care Notebook. Family Voices is working on a health care financing guide for families so families will know how things are financed whether it is CSHS or Medicaid or private insurance. Donene informed everyone they could call her with any recommendations in working with families. Families really enjoy serving on the Family Advisory Council because they feel like they are heard and their recommendations are taken seriously.

#### Medical Home

There was a small grant through the American Academy of Pediatrics that North Dakota applied for. This was a team effort and Myra Quanrud took a leadership role. The group conducted an assessment in three communities with health care providers, community partners, and families to see if there was knowledge about or problems that could be identified with the medical home. There was a lot of interest but also a need for education on the medical home concept. Areas of concern were also identified. After the assessment, community meetings were held to provide feedback to the community partners. Rural Bismarck, Bottineau and the Jamestown communities were targeted.

Dr. Dwelle stated the role of Healthy North Dakota. It's a collaborative that may be worthwhile to discuss whether or not there needs to be an ongoing process. If you're needing an ongoing process of collaborators, contact Melissa Olson. One would have access to some incredible resources like third party payers when you talk about funding issues. There are also some delivery groups that meet regularly and that is the whole point of Healthy North Dakota.

Ms. Millner stated SB 2395 deals with children with Russell Silver Syndrome and a Medicaid waiver. HCR 3054 is a child health study that was selected as an interim study by the legislature. If a person thinks there are things that need to be heard or an opportunity to affect change, this is where they can have a voice.

Tammy encouraged the Council to provide feedback to the Medicaid Pediatric Task Force. Dr. Cook attended one meeting, which was beneficial. If there are issues from the medical providers standpoint, this is another opportunity to have a voice. Therapists have been involved but not many physicians.

Dr. Kerbeshian suggested talking to the Academy of Pediatrics about having someone come.

Ms. Millner stated she was not sure how individuals have been solicited.

Mr. Zentner stated that a lot of people are putting emphasis on what can be done with a Medicaid waiver. There are two types of waivers. One deals with home and community based care and the other one is more of a demonstration process. The problem with both of them is they have to be budgeted. The government is not going to go ahead and approve new programs that are going to cost them more money so they have to be budget neutral. The home and community based care waiver is something that may be looked at. On the home and community based care side, they have to meet institutional requirements. They would normally have to be in a hospital or a nursing home and he doesn't think that is going to necessarily meet the criteria for what a lot of people are talking about as far this special group of kids. They may have to look at an 1115 process, which is a difficult waiver to deal with.

### **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. Fiechtner, Dr. Kerbeshian, Dr. Sommers, Dr. Sobus, Dr. Klava and Dr. Quanrud.

Dr. Wentz asked if everyone was willing to serve another term. Members who were present agreed to continue.

Dr. Klava asked if CSHS has space, whether Dr. Haasbeek could be reinstated on this board.

Dr. Fiechtner and Dr. Sommers will be contacted to determine their interest.