

Children's Special Health Services
Medical Advisory Meeting
Bismarck, North Dakota
May 2, 2015, 8:30 a.m. – 12:00 p.m.

Attendance:	
Appointed Medical Advisory Council members	Thomas Carver, DO; Jacqueline Quisno, MD; Jeffrey Nelson, MD (in place of Sue K. Wink, MD); Sara Jumping Eagle, MD; Blake Feil, DDS; Laura Schield, MD (in place of Ellen Feldman, MD); Kari Casas, MD; Lori Sondrol, MD; Richelle Bautista-Azores, MD
Children's Special Health Services (CSHS) Division staff	Tamara Gallup Lelm, Division Director; Devaiah Muccatira, SSDI Program Coordinator; Kim Hrubby, Program Administrator; Tammie Johnson, Program Administrator; Tina Feigitsch, Claims Processing Specialist; Kodi Pinks, Autism Database Administrator; Diane Bruley, Administrative Assistant; and Carrie Tate, Administrative Assistant
Continuous representation on the CSHS Medical Advisory Council	Courtney Koebele, North Dakota Medical Association; Melissa Schroeder, Family Advisory Council Designee; Sarah Carlson, Family Advisory Council Designee; Joan Connell, MD, CSHS Medical Director; and Clifford Klimpel, (in place of Evelyn Klimpel Family Advisory Council Designee).
Guest Speakers	Neil Scharpe, NDCPD – EHDI; and Katie Bentz, NDDoH – Family Health
Welcome and Introductions	Tamara Gallup Lelm, Children's Special Health Services Division Director, provided a warm welcome and relayed appreciation for the time devoted for the annual Medical Advisory Council meeting and the commitment made by participants to assist the division in its work throughout the year. Introductions were made.
Opening Remarks & CSHS Updates	<p>Tamara Gallup Lelm provided a CSHS update. She relayed that CSHS currently functions with 9 full-time staff and the part-time services of Dr. Joan Connell, CSHS Medical Director. Tina Feigitsch recently accepted the position as CSHS Eligibility & Claims Administrator, a position previously held by Melissa Evans.</p> <p>For the 2015-2017 biennium, the CSHS division budget is expected to be about \$3.0 million. This amount is less than the previous biennium but reflects a realistic picture with expected revenue. Major federal funding sources for the division continue to be the Title V MCH Block Grant and the State Systems Development Initiative grant. General funds are also appropriated through the legislative process. The division will be able to sustain most of its programs but some reductions in contracted projects are anticipated over the next two years.</p> <p>The CSHS division has a two-fold mission: 1) to provide services for children with special health care needs and their families, and 2) to promote or develop health care systems that are family-centered, community-based, and coordinated. A handout was reviewed that provided an overview of the division's nine programs. Participants were informed that the majority of the meeting would focus on the Specialty Care Diagnostic and Treatment Program, where CSHS helps families pay for medical services for their eligible children. For this program, financial eligibility is mandated at 185% of the federal poverty level, which is currently at \$44,863 for a family of four. Families earning more than that amount can still be eligible but need to share in a portion of the costs. Health insurance premiums paid out of pocket are an allowed deduction.</p>

	<p>Several program reports were reviewed with council members including the following:</p> <ul style="list-style-type: none"> • Program Data Report – CSHS served close to 2,450 children in FFY 2014. Over the last few years, this number has ranged from 2,200-2,400. • Health Care Coverage Report – Overall, 93% of children served by CSHS had a source of health care coverage. CSHS is often a secondary payer covering gaps such as co-pays, deductibles, and non-covered services. Since CSHS traditionally serves an “underinsured” rather than an uninsured population, the Affordable Care Act and Medicaid Expansion have had a negligible impact. • Claims Payment Report – In FFY 2014, CSHS paid over \$200,000 in claims through MMIS, which was an increase from the previous year. Payments by condition vary significantly. Over 80% of all CSHS diagnostic and treatment expenditures were paid out for the following conditions: diabetes, cleft lip/palate, seizure disorder, heart conditions, handicapping malocclusion, and tyrosinemia. <p>Looking forward, Tammy shared some of the opportunities and challenges for the division, including:</p> <ul style="list-style-type: none"> • Direct service programs vs. systems – Services for individuals children continue to play an important role in CSHS, although movement to a “systems or more population-based approach” is growing. • MCH Transformation 3.0 – A significant change in the MCH Block Grant occurred this year. These changes in priorities will affect the focus of ND’s future MCH work activities. • Impact of technology – The roll-out of the MMIS Enterprise claims payment system is on the horizon. Over the last several years, CSHS has been involved in design and development of the new system so staff are looking forward to an expected fall 2015 “go-live” date. <p>New ND fact sheets using data from the 2009-2010 National Survey of Children with Special Health Care Needs were also highlighted.</p>
Legislative Updates	<p>A partial list of Legislative bills that CSHS tracked/monitored were reviewed, including:</p> <ul style="list-style-type: none"> • SB 2176 – The ASD expert panel meeting that was convened in October raised concerns that language in NDCC 23-01-41 was potentially too restrictive and might hinder reporting into the ASD database. The panel recommended that the following areas be addressed during the 2015 legislative session prior to the database being fully implemented: <ul style="list-style-type: none"> ▪ The criteria for qualified reporters, ▪ The complete physical evaluation, and ▪ The use of a designee to report. <p>SB2176 did pass and was signed by the governor. It is the department’s expectation to have the ASD database implemented by the end of the biennium. The department is in the process of drafting and finalizing Administrative Rules for the ASD database.</p>

	<ul style="list-style-type: none"> • SB 2012 – DHS budget – Medicaid guidelines act as guidance for service payment within CSHS. Also, what Medicaid does with their provider inflationary increases impacts how CSHS pays providers. There ended up being a 4% and 4% provider increase for the biennium. Family Voices of ND and Federation of Families funding was also introduced in this legislation, and each received \$75,000. CSHS also provides funding to Family Voices of ND. • SB 2259 – experimental drugs – This bill started with a family that has 3 children with serious medical conditions who wanted to try an experimental drug. The legislation would allow a patient to take medication that has passed phase one of the Food and Drug Administration approval process, but is not yet available to the general public. The bill passed, giving families the choice to use experimental drugs; however, insurance companies are not mandated to pay for them. • HCR 3059 – medical marijuana - Families with children that have severe health care needs advocated for this bill. The bill was countered by Attorney General Stenehjem whom had concerns of the potential legal ramifications that occurred in other states where medical marijuana is legal. Dr. Dwelle also had concerns with the safety of children and the detrimental effects it may cause them. This bill was defeated. • SB 2194 – Naturopaths – Dr. Connell worked on this bill with Courtney Koebele from the Medical Association. The concern raised by providers is the lack of training of Naturopaths. They only have a third of the training that Physician Assistant’s and Nurse Practitioner’s receive. The providers didn’t feel that it is safe for Naturopaths to prescribe medications. The bill passed the senate and failed in the house. <ul style="list-style-type: none"> ▪ The state is in need of providers and some people feel that someone is better than no one.
Minutes	Dr. Carver moved to approve the 2014 meeting minutes. Devaiah seconded the motion and all were in favor. The 2014 meeting minutes were approved.
Provider Qualifications, Certification, and Enrollment	<p><u>CSHS provider certification update:</u> Tina gave a brief overview that there were 183 specialists due for re-certification per CSHS database. Of these, 163 were verified and re-certified. Twenty specialists have not re-certified. Tina will be following up on the providers that have not yet re-certified to verify if/when they do so.</p> <p><u>MMIS Enterprise enrollment:</u> With the new MMIS Enterprise system, all providers will need to re-enroll in order to accept Medicaid and/or CSHS payments. For convenience, Medicaid staff sent out a list of providers who haven’t enrolled yet. CSHS staff have contacted some of the specialty providers to offer them technical assistance with this process.</p> <p>In-person provider trainings are being offered in the major hubs of Fargo, Minot, and Bismarck. Web-based trainings will be available going forward. CSHS staff believes that the new system should be more user-friendly. It will give clients the option to access their information on the system.</p> <p>Providers should also be aware that there will be a 4-6 week black-out date before the system goes live, in which claims cannot be processed. Medicaid staff will be sending out more information on this as the date approaches.</p>

	<p><u>Advice on CSHS provider-related issues</u></p> <p><u>Cleft palate team provider participation:</u> With many longstanding physicians retiring, CSHS is having difficulty with new physicians being willing and/or able to participate. The clinic volumes seem to be getting larger in many areas of the state. Some specialized areas of expertise, such as plastic surgeons, are especially hard to recruit, as many do not perform cleft surgeries. Questions were answered regarding the various specialties that staff these clinics, when the clinics are held, how staffing occurs, the reports that are provided to the families, and provider honorarium details. Advice was sought on how participation by providers might be improved.</p> <p>The council suggested more attempts at getting buy-in from administration or the facilities. Other suggestions included new approaches to the clinic day, such as taking an entire day rather than a half-day in Bismarck, or utilizing telemedicine if accessible. Honorariums were said not to be important, since many of the providers are doing these clinics to give back to their communities. The biggest challenge for providers is taking a day away from their clinic patients, so using a “clinic champion,” to stress the need for this service may be more influential than a call from a CSHS Program Administrator.</p> <p><u>Naturopaths:</u> Should they be added to the CSHS provider list?</p> <p>Discussion included:</p> <ul style="list-style-type: none"> • Sanford in Sioux Falls has Naturopaths in the hospital. • It is a good option for people, but has to be monitored. There are only seven currently licensed in the state but they should not be primary providers. Need to think what CSHS would reimburse them for, which would only be an office visit. • Medicaid and other insurance companies do not reimburse so CSHS cannot reimburse. • This is something that should be tabled until the state recognizes them as licensed clinicians. • Needs to be evidence-based.
<p>Newborn Screening and Follow-Up Services</p>	<p><u>Newborn screening update –Katie Bentz</u></p> <p>SB2334 – Newborn screening tests for over 40 conditions in ND. Newborn screening bill updated its language for clarification and transparency for the public. The two terms in the bill language that came into question were licensed and responsible clinician, much discussion with legislators was completed for clarification. Some legislators were in support of adding Naturopaths as a licensed clinician. However, the legislators agreed upon leaving Naturopaths under responsible clinician along with midwives, as they are able to order newborn screenings. Licensed clinicians order the newborn screening as well as provide follow-up care and medical management for children that have positive screening results. Administrative rules are being updated.</p> <p>Family Health Division received a two year grant through Association of Public Health Laboratories (APHL). This will be used for implementing SCID testing as an addition to the newborn screening panel. They will partner with the Iowa lab. The Iowa Lab has already implemented SCID testing, and it is anticipated to be an easy process. CSHS tries to cover diagnostic</p>

and treatment services for any newborn screening condition.

A handout was provided indicating the number of positive results from newborn screening in North Dakota.

Update of hemoglobinopathy traits and physician follow up

CSHS staff provides follow up calls for positive newborn screening test results. Some of the newborns have tested positive for a hemoglobinopathy trait. This was discussed last year at the MAC and it was agreed upon waiting 7-10 days before follow up call to allow the physician time to contact the family. Tammie implemented that change right away, but found that many times the family had still not been notified. The current trend is that the physicians are discussing this with the families at the infant's 8 week checkup. This may be due to the fact that children with hemoglobinopathy traits are not retested until they are 12 months old. The MAC agreed to have staff wait until the child's eight week checkup before calling the parent to discuss services and resources for those infants with hemoglobinopathy traits.

Metabolic food program

Follow up on formula and low protein food: Better Milk was discussed last year at the MAC meeting and it was decided that CSHS could consider this for the Metabolic Food Program if the company was able to give CSHS a better deal on the cost of the formula. There has been no response from the company. CSHS will continue to offer the current metabolic formula in stock. The legislature had intense scrutiny regarding cost issues for the medical food (formula) program. After much discussion the legislature made no changes to the current law.

Care coordination for adults coming back on formula: This group of individuals requires a significant amount of care coordination which is quite time consuming. This is compounded when they have been off of their diet for a number of years. CSHS requests a new prescription for their formula to ensure that CSHS is able to meet their nutrition needs. Over the last year, 2 new adults moved into North Dakota requiring formula for PKU and MSUD.

Early Hearing Detection and Intervention – Neil Scharpe

PCP involvement with EHDI to reduce "Loss to follow-up": EHDI has been a tremendous success funded by a HRSA grant. It currently has a tracking system in place with Vital Records to get all births, including home births. Hospitals are doing a phenomenal job with screenings. However, refer (failed screen) rates have been going up and these infants are not returning. A baby needs to be 24 hours old to allow for clear ears before they can get an accurate OAE reading. Some babies are being discharged before 24 hours of age, especially in the western side of the state. For example, if a child is referred with a plugged ear, or if there are not definitive results, this child should be referred back to audiology. EHDI does the tracking, but the providers do all the work. There are concerns that funding will not continue for ND with a 60% of loss to follow up rate, even though initial screening rates are good. How can ND EHDI involve PCP's to help follow-up improve?

Dr. Carver stated that even with talking to families about their results and setting up the audiology appointment for them, compliance and follow-up was difficult. He found it much more successful having his own hearing screener in

	<p>the office to perform the secondary screening; if they failed then, they were sent to audiology. Several other primary care physicians on the council commented that they were also interested in purchasing their own screener for follow-up on these children. Hospital discharge records are sometimes hard to acquire, so having a screener right in their office would be beneficial.</p>
<p>CSHS Medical Eligibility/Medical Necessity</p>	<p><u>Change Juvenile Rheumatoid Arthritis to Juvenile Idiopathic Arthritis:</u> Courtney Koebele motioned to approve the name change. Dr. Carver seconded the motion. All were in favor. Motion carried.</p> <p><u>Broaden microcephaly to be eligible for treatment services:</u> Currently this is eligible only for diagnostic services. There was a case where a child needed further treatment and CSHS was not able to cover it. Should CSHS broaden to include it under treatment services or keep it only as a diagnostic service?</p> <p>Discussion Included:</p> <ul style="list-style-type: none"> • It was recommended that treatment services be covered. • It was questioned if insurance covers these services and that it could be costly, Dr. Connell responded that insurance companies do cover these services, but CSHS would do gap filling. <p>Dr. Carver motioned to broaden microcephaly to be eligible for treatment services. Dr. Sondrol seconded the motion. All were in favor. Motion carried.</p> <p><u>Collagen Vascular Disorders including but not limited to lupus, dermatomyositis, scleroderma, Sjogren's disease, and rheumatoid arthritis:</u></p> <p>Dr. Carver motioned to broaden the Collagen Vascular Disorders category. Dr. Quisno seconded the motion. All were in favor. Motion carried.</p> <p><u>Addition of psoriasis as an eligible condition:</u> A question was asked if there are funds to add this as an eligible condition. Tammy responded that the conditions CSHS often covers are rare and the family has to be financially eligible as well. These decisions will not "break the bank".</p> <p>Dr. Carver motioned to approve this addition. Dr. Bautista-Azores seconded the motion. All were in favor. Motion carried.</p> <p><u>Auditory Processing Disorders in addition to standard Hearing Loss:</u> Would CSHS cover this as a medical condition?</p> <p>Discussion included:</p> <ul style="list-style-type: none"> • It was stated that an audiologist alone cannot diagnose this condition because of its complexity. A proper diagnosis is difficult and the medical treatments are unclear. This is more of a clinical diagnosis but it should be on the covered list. • Some chiropractors are doing some treatments for this. • Questioned if this would be in the realm of Autism Spectrum Disorders. <p>Dr. Jumping Eagle would vote to add this to the list, but to put stipulations on how it is diagnosed. Dr. Quisno motioned to have a further study on this subject. Dr. Bautista-Azores seconded the motion. All were in favor. Motion carried to bring back to next year's meeting after further study is done.</p>

	<p>Advice was sought on terminology to expand coverage for chronic lung/lower airway conditions including chronic lung disease, chemical pneumonitis, and subglottic stenosis. Would exclude laryngotracheomalacia and common acute conditions that can be recurrent. Should CSHS expand this?</p> <p>Discussion included:</p> <ul style="list-style-type: none"> • Why is this being brought up? Dr. Connell stated that there was a case where it was not asthma, since the child was 3 months old. If this was expanded CSHS would be able to cover this. <p>Dr. Sondrol motioned to expand coverage. Dr. Nelson seconded the motion. All were in favor. Motion carried.</p>
<p>Financial Eligibility, Covered Services and Reimbursement Issues</p>	<p><u>Five-year summary of eligible individuals meeting \$20,000 limit:</u> Kim gave an update on 5 year summary. In the last five years, only one child has reached this limit. CSHS was the child's only source of coverage. The child had a cardiac condition and maxed out in 2011. He had surgery out of state including hospitalization and maxed out care for the remaining months of his financial review period, possibly leaving them with a very costly bill for hospitalization and surgery. Staff worked with the local CSHS county worker to have them apply for Medicaid and possibly get retro authorization for out of state care to avoid maxing out CSHS coverage. The family did not follow through on the application</p> <p>2 children were monitored for possible high dollar payments this year.</p> <p>20 y/o with Seizure Disorder with no primary insurance coverage for needed medication and a few office visits with labs.</p> <ul style="list-style-type: none"> • As of the end of April, a little over \$13,000 has been paid out. Individual had a cost share for a few months, so CSHS paid a little bit less than the previous year. • Turns 21 in May. Likely will not exceed \$20,000. • CSHS staff have been monitoring amount paid out very closely and keeping family & county informed <p>15 y/o uninsured child who was receiving diagnostic services for evaluation of hearing/vision/altered mental status episodes. In-state visits and testing were covered and further out-of-state evaluations including inpatient EEG resulted in CSHS paying roughly \$13,000. Also eligible for heart conditions.</p> <ul style="list-style-type: none"> • Family is not expected to apply for treatment. <p><u>Feedback on CSHS diagnostic re-evaluation process:</u> Staff completed a chart audit to evaluate if all open cases still needed Diagnostic services. After working with the local county offices, those not currently active were closed. An annual re-evaluation process was implemented to keep only the active cases open, and this has been working well to keep our numbers accurate.</p> <p><u>Exploring diagnostic policy:</u> An overview of the differences between the Diagnostic Program and Treatment Program was provided. It was pointed out that for the Diagnostic Program, there is no financial eligibility. Currently, "diagnostic services are used to initially diagnose a child's potentially eligible condition. <i>Diagnostic services can also be used when the medical condition is known to find out whether or what kind of treatment is recommended.</i>" The last portion of this statement sometimes causes confusion within CSHS, as CSHS wants to be fair and consistent. But sometimes, views on what qualifies</p>

	<p>as furthering the treatment plan can be quite difficult to differentiate. Should this be changed, or how can CSHS make it clearer?</p> <p>Families can seek multiple opinions if they are warranted, and cannot jump between the Treatment Program and Diagnostic Program for the same condition.</p> <p>Dr. Feil stated that leaving that portion of the policy as-is would possibly lead to insurance manipulation, so suggested taking it out. No other recommendations from the council were received.</p> <p><u>Coverage of post mortem diagnostic testing:</u> Discussed genetic testing for an infant that passed away from a metabolic disorder after being discharged home. A request was made to cover genetic testing after the infant's death. CSHS Staff researched postmortem coverage. Medicaid and ND Blue Cross Blue Shield (BCBS) do not cover any testing after death.</p> <ul style="list-style-type: none"> • Decision: It was determined that CSHS will not cover genetic testing through the Diagnostic Program after the death of an infant. • Discussion/Rationale: It was determined that CSHS would not cover the costs of genetic testing after the death of an infant that had a positive NBS result for a metabolic disorder. Reviewed Medicaid and Blue Cross Blue Shield coverage and they do not cover any costs incurred after the death of a patient including autopsy or genetic testing. The question was posed that CSHS would have covered the cost of genetic testing if the child had lived, and this would be accurate. However, payment for services would cease upon death and the case is closed on the date of death. The tissue and blood samples were obtained after death during the autopsy, and would be sent to an out of state lab for determination after the documented date of death which would leave that ineligible for payment. <p><u>Cochlear implants:</u> Previously, neither Medicaid nor CSHS had a policy regarding cochlear implants, however; CSHS covered them on a case-by-case basis. Medicaid now has a cochlear implant policy. Should CSHS develop a policy on this as well or should the CSHS policy differ from Medicaid's?</p> <p>Discussion included: Council member shared that in his opinion Medicaid's policy is adequate. Therefore, CSHS could continue to cover these on a case-by-case basis and use Medicaid's policy as guidance. Dr. Nelson shared information with the council that Dr. Yorgason, in Bismarck, and Dr. Miller, in Fargo, are doing cochlear implants. It is a wonderful option now available in North Dakota, previously many families needed to travel out of state.</p>
Programmatic Updates	<p><u>Autism database update:</u> With the passing of SB 2176, the department will follow the formal rule making procedure. The department is finalizing the Administrative Rules for the ASD database. Staff has met with the Attorney General's office twice to discuss the rules.</p> <ul style="list-style-type: none"> • The ASD database brochures were provided as handouts. The provider brochures are technical and discuss the reporting requirements for reporters. The family brochures give an overview about the ASD database and its purpose. Feedback about the drafted brochures was received from expert panel members, Family Voices and Pathfinders. • A draft fillable pdf version of the report form was handed out and discussed. The electronic version of the report

	<p>form will be the preferred method of submission. It is being developed by staff in Disease Control and a tangible product should be available in a couple of weeks.</p> <p>Advice was sought on how to spread awareness and educate reporters regarding the ASD database. The department will do a news release prior to the effective start date. Contact has been made with state practice boards about including ASD database information in newsletters and providing a notice on their websites.</p> <ul style="list-style-type: none"> • Recommendations from the council included sending out a letter to all providers in the state, including the medical association and hospital association. It is also important that patients receive resources about the ASD database. <p><u>COIN</u>: is a platform designed to have strategies to reduce infant mortality and observe data. MCH priorities handout show priorities that are set.</p> <p><u>Contract update</u>: Tammy discussed CSHS is currently going through a grant process to pass money from a federal level to the state level. CSHS uses this funding to fund 10 varieties of multidisciplinary clinics with this. This cycle CSHS is looking at more family participation groups, focus on public health, and medical home. CSHS did have to eliminate the care coordination contract. Does the council have any other ideas?</p> <p>Discussion included:</p> <ul style="list-style-type: none"> • A question was asked if the location of the asthma clinic can be rotated. Possible locations included Dickinson, Minot, or other areas to make traveling easier for families coming from long distances. Dr. Connell responded that they are working on possibly doing this and maybe adding a clinic at an IHS site. • The Asthma tracker clinic tool is a big plus for the state. Insurance companies do not want to cover the asthma tracker clinic tool even though it reduces hospitalization by 98%. • Another question was asked if CSHS has any participation with the mobile dental clinic. However, CSHS does not directly participate in the mobile dental clinic. CSHS does provide links to information on the mobile dental clinic in some of our brochures. • Are families being overwhelmed with multiple referrals to services or duplicating services? Early Intervention is a great tool for families to access services. Other private services are also available to them. • There is a greater result when the family is involved.
Closing Remarks/Wrap-Up	<p>Four council members have terms that will be expiring this year. They include Dr. Wink (Dr. Nelson agreed to take that term), Dr. Feldman (Dr. Schield agreed to take that term), Dr. Quanrud – yes will continue, and Dr. Fernandez – Dr. Connell will contact.</p> <p>Dr. Connell closed the meeting after giving a warm thank you to the council for all their hard work and support.</p>