

Children's Special Health Services  
Medical Advisory Meeting  
Bismarck, North Dakota  
April 30, 2016, 8:30 a.m. – 12:00 p.m.

Attendance:	
Appointed Medical Advisory Council members	Thomas Carver, DO; Jacqueline Quisno, MD; Jeffrey Nelson, MD; Sara Jumping Eagle, MD; Blake Feil, DDS; Laura Schield, MD; Kari Casas, MD; Lori Sondrol, MD; and Joanne Luger, DDS
Children's Special Health Services (CSHS) Division staff	Tamara Gallup Lelm, Division Director; Devaiah Muccatira, SSDI Coordinator; Kim Hruby, Program Administrator; Tammie Johnson, Program Administrator; Tina Feigitsch, Claims & Eligibility Administrator; Nicole Roller, Medical Claims Service Specialist; Kodi Pinks, Autism Database Administrator; Diane Bruley, Administrative Assistant; and Vanessa Peach, Administrative Assistant
Continuous representation on the CSHS Medical Advisory Council	Sarah Carlson, Family Advisory Council Designee; Joan Connell, MD, CSHS Medical Director; Clifford Klimpel, Family Advisory Council Designee; and Dawn Mock, Medical Services Designee
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. Vanessa Peach and Nicole Roller are two of the full-time staff members that are new to the CSHS office within the last year.</p> <p>For the 2015-2017 biennium, the CSHS division budget is about \$3.1 million. 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 year. With the state budget, the department absorbed a 4.05% reduction in general funds for the 2015-2017 biennium. The 2017-2019 biennium's budget for the Health Department will be developed over the next three months. The Governor should have the directives available in early May and the base budget is due to Office of Management &amp; Budget the middle of August. At about the same time, departments can submit optional requests.</p> <p>The CSHS division has a two-fold mission: 1) to provide services for CSHCN's 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 for a</p>

	<p>family of four is currently \$44,955. 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"> <li>• Program Data Report- CSHS served close to 2,500 children in FFY 2015, which is similar to last year.</li> <li>• Health Care Coverage Report- Overall, 92% of children served by CSHS had a source of health care coverage. CSHS frequently is a secondary payer covering gaps such as co-pays, deductibles, and non-covered services.</li> <li>• Claims Payment Report- In FFY 2015, CSHS paid over \$190,000 in claims through the Medicaid Management Information System (MMIS), which was a decrease from the previous year. Over 80% of all CSHS diagnostic and treatment expenditures were paid out for the following conditions: diabetes, seizure disorder, cleft lip/palate, hearing loss, and handicapping malocclusion.</li> </ul> <p>Looking forward, Tammy shared some of the challenges and opportunities for the division, which include:</p> <ul style="list-style-type: none"> <li>• Direct service programs vs. systems- Services for individual children continue to play an important role in CSHS, although movement to a “systems or population-based approach” is growing. Changes in federal and state priorities will affect the focus of North Dakota’s future MCH work activities.</li> <li>• Impact of Technology- The ND Health Enterprise MMIS will continue to have an impact on CSHS. Other opportunities may arise with electronic health records as “informatics” capacity expands.</li> <li>• 2017 Legislative Session- Future policy and available resources will be determined.</li> <li>• Emerging Issues- Opioid/heroin abuse, the Zika virus, medical marijuana, environmental health, etc.</li> </ul> <p>A poster was highlighted that staff helped create on Adverse Childhood and Family Experiences among American Indian Children in ND. Historical trauma and ACE’s contribute to this disparity and long term health consequences.</p>
<p>Medical Services Update</p>	<p>Dawn Mock, the Medicaid Program Integrity Administrator, attended and gave an update from the Medical Services Division within the ND Department of Human Services. Dawn disseminated the 2015-2017 budget allotment for members to review. She also discussed some of the issues with the ND Health Enterprise MMIS which include:</p> <ul style="list-style-type: none"> <li>• Issues with dental providers and hospital claims</li> <li>• People processing the claims are also having to do problem-solving which is making the processing of claims take about three times longer</li> <li>• Had some issues with providers’ taxonomy numbers and NPI numbers that didn’t match</li> </ul>
<p>Minutes</p>	<p>Dr. Carver moved to approve the 2015 meeting minutes. Dr. Quisno seconded the motion and all were in favor. The 2015 meeting minutes were approved.</p>
<p>Provider Qualifications, Certification, and Enrollment</p>	<p><u>CSHS provider certification update</u>: Nicole relayed there were 254 specialists due for recertification in the CSHS database. Of these, 244 were reviewed and recertified. Ten specialists have not re-certified. There were also sixteen specialists that were removed from the specialist list as they have either retired, moved out of state, or passed away.</p>

	<p><u>ND Health Enterprise MMIS:</u></p> <ul style="list-style-type: none"> <li>• Provider enrollment has initially been challenging with the new system. If a provider did not complete the enrollment paperwork prior to go-live, they are not open in the new system. Providers also have to do applications for all types of services.</li> <li>• There were some initial concerns with the call center and uncertainty whether providers were being routed correctly when inquiring about CSHS. Call scripts were sent to the center staff to encourage accurate routing. In talking with some providers, they are calling CSHS directly versus using the call center.</li> <li>• There have been several claims processing issues and edits with the new system. There are different requirements for claims processing. Claims now require provider and facility taxonomy numbers be entered on the claim. The requirements are more stringent with reason/remark codes that are put on the claims for the provider remittance advices. CSHS is not able to adjust or override those codes when doing claims processing. Medicaid rules don't always match with the policy/procedures that are set up for CSHS, which have caused additional challenges. In these situations, CSHS is working with the Department of Human Services (DHS) and Xerox staff to either change the edit logic or the system as a whole to get the claims to process correctly. More manual work is required with the new system for CSHS. Staff manually keys in all eligibility, third party liability, recipient liability, etc. for each client. Although staff are currently behind on claims processing and payment, they are working hard to get them caught up. Providers are asked to be patient as staff work to resolve the issues and were encouraged to contact CSHS as problems arise.</li> <li>• Financial reports have initially been problematic, especially with claims that have a cost share.</li> </ul>
<p>Newborn Screening and Follow-Up Services</p>	<p><u>Newborn Screening Results for 23-24 Week Gestation and Follow-Up</u>  A brief update of the process for newborn screening and CSHS follow up was provided to Medical Advisory Council members. Discussion centered around the presumptive positive results on 23-24 week preterm babies. CSHS decided that these families would not be contacted or followed by CSHS as they are being followed by the hospital social worker and case manager. Many of these results may be elevated just due to their extreme prematurity. The Medical Advisory Council was in agreement.</p> <p><u>Hemoglobinopathy Results with one-year follow-up</u>  There has been a marked increase in hemoglobinopathy traits over the last two years. These children have the traits, but not the diagnosis. Many times physicians are not discussing this with the families until the child's 8-week checkup, and are rechecking them at 1 year of age. These are not active cases so CSHS will not be contacting families.</p> <ul style="list-style-type: none"> <li>• Dr. Jumping Eagle suggested discussing an option of long-term follow/tracking up as many children on or around the reservations may be missed due to moving and not following up with a provider for follow-up testing. The council suggested some type of alert that is available for electronic records. This may be difficult as the electronic records systems do not interface with other facilities. This will be discussed with the Newborn Screening Advisory Council. Other issues discussed included follow-up for infants with Hepatitis C and drug-exposed infants. Issues arise with the latter as providers are not receiving hospital discharge summaries until after the patient is seen at the clinic.</li> </ul>

	<p><u>Long-term follow-up</u> CSHS received a positive newborn screening for a baby with PKU within the last week. An average of 20 to 25 individuals with PKU or MSUD are actively being served.</p> <p><u>Newborn Screening and SCID (Severe Combined Immunodeficiency) conference</u> The SCID Conference is scheduled for May 20, 2016 at the Ramada Inn in Bismarck. A flyer was provided to the council attendees. SCID will be added to the newborn screening panel on July 1, 2016. The newborn screening fee will go up to \$75.00.</p> <p><u>Metabolic Formula Cost Increase</u> The council was provided a list of medical food (formula) that is available through CSHS. Between 2015 and 2016 formula prices have increased between 2% to over 11% depending on the company and the type of formula.</p> <ul style="list-style-type: none"> <li>• Discussion included developing a formulary.</li> </ul> <p>CSHS approved a request from the Sanford Metabolic clinic to use some of their Metabolic Clinic contract funding to support Dr. Cathy Breedon's attendance at the International Metabolic Dietitians Conference in Arizona. Another Sanford staff person will also be attending the conference to take advantage of time for cross-training and mentoring. CSHS has also requested that Dr. Breedon provide a presentation for CSHS/NDDoH or the metabolic clinic team to share the new knowledge gained.</p> <p><u>Early Hearing Detection and Intervention (EHDI) –</u> The ND Early Hearing Detection and Intervention program (ND EHDI), has undergone some major changes in the last year. There are now only two EHDI Follow-Up Coordinators for all the birthing hospitals in ND. They have been separated into the eastern and western halves of the state. Also, Jerusha Olthoff, who was formerly only responsible for the CDC (data) portion of the ND EHDI Program, is now the Principal Investigator for the entire ND EHDI Program, which includes the HRSA (programmatic component) and CDC (data component).</p> <p>EDHI handouts were included in the packet that reflected how individual facilities were doing with birth hearing screenings and follow-up. Promotional posters were also available for council members. CSHS encouraged physicians to discuss the results of the baby's newborn hearing test at the baby's first checkup (typically 2 weeks of age).</p>
<p>CSHS Medical Eligibility/Medical Necessity</p>	<p><u>Coverage of diabetic pumps and supplies</u> CSHS is currently having some difficulties with assisting in gap-filling for a few families. The durable medical equipment (DME) provider that they were referred to by their provider for the pump and supplies is not enrolled with ND Medicaid, which impacts CSHS's ability to pay claims for the equipment/supplies. The two companies that we are currently aware of are Animas and Insulet Corp (Dexcom pump). Some issues this is causing are:</p> <ul style="list-style-type: none"> <li>• Claims are being denied due to provider not being enrolled.</li> <li>• Claims are not being submitted to CSHS as the provider does not bill a secondary insurance.</li> </ul>

- Families are having to pay a lot of out-of-pocket expenses.
- Some things CSHS discovered while trying to resolve these issues are:
- The DME providers state that they want to enroll with ND Medicaid but say they can't. An Insulet Corp representative stated the reason they decided not to enroll is due to ND state rules and regulations.
  - When checking to see if a local pharmacy would be able to order the supplies on behalf of the family and then submit the claim to CSHS, the DME provider stated it would be possible only if the pharmacy is contracted with them, and at this time there are only four in the US that contract with OmniPod.
  - Currently Medicaid will authorize a new pump as medically necessary if the client is not able to get the supplies that they need for their current pump. However, since the primary insurance is able to pay for the supplies with these providers, CSHS may not be able to get the medical necessity piece approved to change the pumps.
  - The medical providers are verifying that the primary insurance covers the pumps and supplies through the DME provider, but are not checking if the secondary payer is able to pay. Thus, CSHS is struggling to be the gap filler for the families.

The Council discussed these issues and concluded that CSHS should do more research. They also asked that CSHS work on improving the availability of insulin pump supplies for Medicaid patients who have non-Medtronic insulin pumps, as well as a better explanation as to why this is such a big issue. This will be done as a short term goal, and the findings will be emailed out to the members of the council as they are concluded. CSHS will also bring forward information on state rules and regulations and revisit this issue at next year's meeting.

#### Continuous glucose monitoring for Type 1 diabetes mellitus to optimize HgbA1C

Dr. Thurlow had asked Dr. Connell to address this issue with the Medical Advisory Council. Dr. Connell disseminated articles to the Council to review that she was given by Dr. Thurlow. There was discussion about continuous glucose monitoring being covered by certain insurances. Dr. Thurlow had said that Sanford is covering this but Dr. Connell was unable to find it in writing anywhere. Dr. Sondrol stated she has many patients where their insurance covers it; however, some insurance require a referral to an endocrinologist, or some only cover for hyperglycemia. The council would like more information on how much of a financial impact this would have on CSHS. Dr. Connell and CSHS staff will do further research and share that with the council via email when they are finished. This will be discussed again next year at the 2017 meeting.

#### Hydroxocobalamin injections for methylmelonic acidemia

This was an interesting circumstance, since this is a very rare condition. The child had been receiving medical care out of state. Upon returning to North Dakota, it was found that the patient required this special compounded injection. CSHS experienced several roadblocks:

1. Dad lost his job while the child was out-of-state and thus lost their primary health insurance, which led to the need for ND Medicaid.
2. Although ND Medicaid stated that they understood the medical necessity, due to federal regulations, they were unable to cover the needed monthly medications (over \$200/month). If at least one ingredient in a medicine is not

	<p>covered by Medicaid, the entire medicine is denied.</p> <p>3. Dakota Pharmacy in Bismarck is the only pharmacy able to compound this medication. The family lives in Minot, which necessitated shipping medications or the family finding a way to pick it up. CSHS gap-filled and got the medicine to the client. The family does have insurance coverage again now.</p> <p><u>Approved descriptors of 2015 added conditions</u> The attendees were asked to review the descriptors of the 2015 added conditions. There were no suggested changes. Dr. Jumping Eagle moved to accept the descriptors and Dr. Sondrol seconded the motion. All members were in favor of adding the descriptors as written for the 2015 added conditions.</p>
New Conditions	<p>Dr. Connell explained the process of adding new conditions to the CSHS medical condition list. They must be chronic, complex, and severe and have effective interventions available to treat the condition. The conditions that are being brought forward are due to cases that have arisen.</p> <p><u>Thromboembolism-Thrombosis/Cerebral Vascular Accident in Factor V Leiden (no eligible issue)-</u> The attendees were asked to review the handout that explained Thromboembolism, and what CSHS would exactly be covering if it was added to the covered condition list. It was asked if there were any questions on the topic and there was some discussion on coverage. Dr. Shield moved to approve adding Thromboembolism to the covered condition list and Dr. Carver seconded it. All members were in favor to have Thromboembolism added to the covered condition list.</p> <p><u>Hypopituitarism-Lori Sondrol Motioned and Quanrud seconded</u> Attendees reviewed the handout that explained what Hypopituitarism is and what CSHS would be covering if it was added to the covered condition list. CSHS does not foresee this being a great expenditure, and will still have hypothyroidism and hyperthyroidism on the condition list. There has only been one case within CSHS since Dr. Connell has been here. Dr. Sondrol moved to approve adding hypopituitarism to the covered condition list and it was seconded by Dr. Quanrud. All members were in favor of adding Hypopituitarism to the covered condition list.</p> <p>Dr. Carver would like to look at adding blindness and septo-optic dysplasia as a covered condition.</p> <p><u>Auditory Processing Disorders:</u> CSHS brought this condition to the Council at the May 2015 meeting. CSHS was asked to pay for diagnostic testing on a child, which ultimately ended in the diagnosis of an auditory processing disorder. Although CSHS was able to cover many of the diagnostic tests, some were denied since auditory processing disorder was not a covered condition. After discussion during the 2015 Medical Advisory Meeting, the committee agreed that since it was a complex disorder to diagnose, CSHS staff should do additional research on this condition and bring the information back to the committee for the 2016 meeting.</p> <p>As explained on the handout, an auditory processing disorder is hard to diagnose. Groups of tests must be completed for hearing, neurologic, behavioral, and dichotic (speech). In the past, CSHS was able to cover the hearing and neurologic tests,</p>

	<p>since there were applicable medical components. Neither ND Medicaid nor ND BCBS have specific policies addressing auditory processing disorder. However, CSHS found a BCBS policy from the state of New York (purple handout), which addresses why testing for an auditory processing disorder is not covered.</p> <p>After the new information was presented, members discussed that an auditory processing disorder can be confused with autism, there is no true diagnostic test for it, and that it doesn't meet the CSHS criteria to add it. Dr. Quanrud moved that it not be added as a covered condition and Dr. Shield seconded the motion. All members were in favor of not adding Auditory Processing Disorder to the covered condition list.</p>
<p>Programmatic Updates</p>	<p><u>Autism database update:</u>          Kodi gave the following overview of the Autism database:</p> <ul style="list-style-type: none"> <li>• During the 2013 legislative session, House Bill 1038 was passed. The Department was given the responsibility of establishing and administering an ASD database that includes a record of all reported cases of ASD in the state. The Department was required to convene an ASD expert panel and develop administrative rules.</li> <li>• The expert panel was convened in October 2014, to establish who is qualified to report a case of ASD into the database and to address other reporting requirements. The ASD expert panel raised concerns that language used in NDCC 23-01-41 was potentially too restrictive and might hinder reporting into the ASD database; therefore, they made recommendations that those issues be addressed during the 2015 legislative session before the ASD database was implemented.</li> <li>• The proposal and passage of Senate Bill 2176 during the 2015 legislative session addressed concerns raised by the ASD expert panel.</li> <li>• The Administrative Rules process was completed in May 2015.</li> <li>• The development of the database and ASD report form, available as a pdf and electronically, took almost two years. The Department was able to use staff from the Division of Disease Control to develop the database in order to save money and build staff capacity. The database officially went live on February 8, 2016.</li> </ul> <p>Since the go live date, there have been a total of 86 ASD cases reported into the database. Thirteen were submitted online via the electronic version and 73 were on the pdf form that gets submitted via mail or fax.</p> <p>Some concerns that have arisen are:</p> <ul style="list-style-type: none"> <li>• The report form is too long and extensive. It is a time burden on providers.</li> <li>• The report form collects too much personal information.</li> <li>• Multiple reporters reporting on the same person is redundant and inefficient.</li> <li>• Perceived ethical violations based on the American Psychological Association's Ethical Principles of Psychologists and Code of Conduct, American Counseling Association's Code of Ethics, and National Association of Social Worker's Code of Ethics.</li> </ul>

	<p>Kodi has been working on addressing these concerns. She met with the Children's Special Health Services Division Director, Deputy State Health Officer, and State Health Office of the North Dakota Department of Health (NDDoH) on March 24, 2016 to give them an update about the Autism Database. Their conversation focused primarily on concerns expressed by mandatory reporters regarding perceived ethical violations based on the APA's Ethical Principles of Psychologists and Code of Conduct and the need for clarification with the NDDoH's policies regarding research. Similar concerns were brought up by LPCCs and LICSWs.</p> <p>Claire Ness, from the Attorney General's (AG) office met with attorneys representing the ND State Board of Psychologist Examiners, ND Board of Counselor Examiners, and ND Board of Social Work Examiners. The attorneys believe it is accurate to say the regulations allow psychologists, social workers, and counselors to submit ASD reports because they are required by law. However, there may be concerns that submitting reports will "harm" patients, which is prohibited under their code of conduct (which is incorporated into regulations). Only the practice boards can determine whether the mandatory reporting of ASD is considered harmful.</p> <p>There was discussion about the reports and if they can be submitted partially completed, which they can be. There was also discussion on some of the criteria that the report requires and how the system could flag you if some of that information (e.g., birthdate) has already been entered into the database to try and prevent duplicate entries. There was also discussion that perhaps it was started too broadly and should have focused collection on those under the age of 18. It was recommended by the council that there be an Advisory Council formed to help address issues.</p> <p>Kodi has received phone calls from families about the database. After discussing the purpose of the database and answering their questions, many of the families feel better about it and see its future benefits.</p> <p>It was suggested that Autism be added to the covered condition list and it was asked that CSHS do some research to determine the cost of adding it to the covered condition list. This will be looked into and the findings will be brought to the 2017 MAC meeting to present to the members.</p>
<p>Financial Eligibility, Covered Services and Reimbursement Issues</p>	<p><u>Five-year summary of eligible individuals meeting \$20,000 limit</u></p> <p>One child was monitored for possible high dollar claims payments this year. The individual was a 15-year-old uninsured child who was receiving diagnostic services for evaluation of epilepsy, hearing loss, and a heart condition. The diagnosis of epilepsy and hearing loss were ruled out. However, the child did have a heart condition which resulted in surgery at the University of Minnesota and follow-up care. These services resulted in CSHS paying roughly \$17,000. The family has since closed effective 11/5/15, as no annual diagnostic application was completed.</p> <p>In the last five years, no child has reached the \$20,000 limit. Last year CSHS monitored two children who had claims paid of roughly \$13,000 each.</p> <p>CSHS is paying as primary for several children and is doing care coordination to try to connect families with insurance</p>

	<p>options.</p> <p><u>Update on CSHS diagnostic policy revision</u></p> <p>Implementing a new policy requiring diagnostic clients to be re-evaluated on an annual basis has ensured that our client list only consists of those clients that are actively utilizing diagnostic services. This has improved from years past when clients could remain open for diagnostic services for several years, even though they were not utilizing them. CSHS staff plan to continue assessing the Diagnostic Program for fairness with implementation, and may consider making further changes down the road to fine-tune the program even further.</p>
<p>Closing Remarks/Wrap-Up</p>	<p>Seven council members had terms that expired this year. They included Dr. Thomas Carver, Dr. Sara Jumping Eagle, Dr. Jacqueline Quisno, Dr. Lori Sondrol, Dr. Blake Feil, Dr. Richelle Bautista-Azores, and Dr. Kari Casas. All of the members whose terms were expiring have agreed to commit to another two-year term.</p> <p>Dr. Connell closed the meeting after giving a warm thank you to the council for all their hard work and support.</p>