Children’s Special Health Services  
Medical Advisory Council Meeting  
Bismarck, North Dakota  
May 6, 2017, 8:30 a.m. – 12:00 p.m.

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<th>Attendance:</th>
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<tr>
<td>Appointed Medical Advisory Council members</td>
<td>Thomas Carver, DO; Jacqueline Quisno, MD; Jeffrey Nelson, MD; Blake Feil, DDS; Laura Schield, MD; Kari Casas, MD; Lori Sondrol, MD; and Joanne Luger, DDS</td>
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<td>Children’s Special Health Services (CSHS) Division staff</td>
<td>Tamara Lelm, Division Director; Devaiah Muccatira, SSDI Coordinator; Kim Hruby, Program Administrator; Tammie Johnson, Program Administrator; Tina Feigitche, Claims &amp; Eligibility Administrator; Nicole Roller, Medical Claims Service Specialist; Kodi Pinks, Autism Database Administrator; Becky Weinberger, Administrative Assistant; and Beth Pritchert, Administrative Assistant</td>
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<td>Continuous representation on the CSHS Medical Advisory Council</td>
<td>Joan Connell, MD, CSHS Medical Director; Sarah Carlson, Family Advisory Council Designee; and Moe Schroeder, Family Advisory Council Designee</td>
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<td>Additional Participants</td>
<td>Mylynn Tufte, State Health Officer and Chris Jones, DHS Executive Director</td>
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Welcome and Introductions  
Tamara 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. Mylynn Tufte also provided introductory remarks on behalf of the North Dakota Department of Health.

Opening Remarks & CSHS Updates  
Tamara Lelm provided a CSHS update. She relayed that CSHS currently functions with nine full-time staff. In addition, CSHS has a shared administrative assistant that works with the division on a very limited, part-time basis and the CSHS Medical Director, Dr. Joan Connell, who also has responsibilities within the NDDoH as a Field Medical Officer.

For the 2015-2017 biennium, the CSHS division’s budget appropriation was $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. The division also receives general funds, the majority of which are used as required match for the federal MCH Block Grant.

Final schedules for the upcoming biennium are not yet available by division but the NDDoH as a whole will receive an appropriation of about $200 million with a general fund decrease of 16.2% and the elimination of 8 FTE. Federal funding uncertainty also makes planning more challenging. Congress recently passed a federal funding bill to keep the government running through September 30, 2017. This Omnibus 2017 appropriations bill unexpectedly included a $3.5 million increase
for the MCH block grant. The increase is to fund a study focused on improving child health through a statewide system of early childhood developmental screenings and interventions. Priority will be given to States with high rates of poverty among children under age five, low rates of early childhood developmental screenings, and high rates of low birthweight infants with resultant complications of prematurity, developmental delays, and other health problems in early childhood. A successful program is expected to involve leaders in early childhood wellbeing, including State officials in health and education as well as medical specialists in pediatrics. The outlook for FFY 2018 which starts October 1, 2017 is also uncertain. The President’s budget includes deep cuts for the Department of Health and Human Services, which houses HRSA and the MCHB (17.9% decrease from 2017 CR level). More details are expected mid-May.

Also in the news is discussion on the future of health reform with passage by the House of Representatives of the American Health Care Act.

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. The majority of the meeting will focus on advice for the Specialty Care Diagnostic and Treatment Program. It’s through this program that CSHS helps families pay for medical services for eligible children. The Legislature mandated financial eligibility for this program at 185% of the Federal Poverty Level (FPL) which equates to $45,510 annually ($3,793 monthly) 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.

Several program reports were reviewed with council members including the following:

- Program Data Report - CSHS served close to 2,500 children in FFY 2016, which is similar to the previous year.
- Health Care Coverage Report - Overall, 92% of the children served by CSHS had a source of health care coverage, about two-thirds of which was through private insurance coverage. Frequently, CSHS is a secondary payer that fills the gaps for what other payers do not cover often for an “underinsured” population (e.g., co-pays, deductibles, non-covered services, etc.). Not quite one-third of the children served were Medicaid-eligible.
- Claims Payment Report – CSHS paid the following in claims through the Medicaid Management Information System (MMIS) over the last three federal fiscal years
  - 2014 - $214,800
  - 2015 - $194,698
  - 2016 - $144,757

Claims payment is lower than usual this year due to a backlog and catch up with utilization of the ND Health Enterprise MMIS and issues with provider claims submissions.

2017 Legislation Review:

- SB 2004 – Department of Health budget
- HB 2012 – Department of Human Services budget
- HB 1187 – Metabolic food for males to age 26; $31,000 fiscal note with no appropriation
| Medical Services Update | The Department of Human Services (DHS) and Medical Services are important partners to CSHS and the ND Department of Health. Maggie Anderson, the Medical Services Director from the DHS, was not able to attend the meeting, but did provide an update for Tammy Lelm to share. The update included information on: 1) Legislation, 2) Waivers, 3) Health Tracks, 4) Therapy, and 5) Coding. Chris Jones, the new DHS Executive Director, provided some remarks on behalf of DHS. Mr. Jones went over the 2016-2017 DHS budget allotment. He also discussed some of the issues with the ND HE MMIS and what is being done to address them. DHS will hold a strategic planning meeting on 5/9/17. |
| Provider Qualifications, Certification, and Enrollment | Review of required qualifications and provider enrollment process: Effective 10/5/15 with the new ND Health Enterprise MMIS, all providers were required to enroll with ND Medicaid (MA) in order to be reimbursed for services. This included providers such as lab techs, anesthesiologists, x-ray techs, etc. If providers are not enrolled with ND MA, CSHS is not able to reimburse them. CSHS is not requiring all providers to be included on the provider blue list, but they do still need to enroll with ND MA. ND MA enrollment has been an issue for a few providers; however, most of them are from out-of-state. The enrollment process is done electronically. The approval process has gotten easier and faster since go-live. CSHS provider certification update: There were 295 specialists due for re-certification based on information in the CSHS database. Of these, 255 were verified and re-certified. Seven specialists have not re-certified which include two family practice physicians, one internist, and four pediatricians. There were also 19 specialists removed from the specialist list as they have either retired, moved out of state, or passed away. |
| Financial Eligibility, CSHS Covered Services, and Reimbursement Issues | Financial eligibility for self-employed: CSHS received an inquiry from a family regarding the amount of their monthly cost share that was based off their annual income, which was $4,966/month. It is CSHS policy to use the adjusted gross income for farm families and small business owners versus the total gross income that is used for all other families. This family indicated that even by using the adjusted gross income, CSHS was not taking into consideration the amount that the family was actually living on. After discussion within the office, it was determined that the adjusted gross income be used for these |
families because they are able to count more deductions when filing their yearly income tax. This will make it fairer in regard to the eligibility guidelines for cost share with the families that have to use their total gross income.

There is a concern on the accuracy of the financial data forms as some are not being completed correctly. If new guidelines are created for select families, filling out the financial data forms may be even more confusing. Members were asked for suggestions as how to calculate cost share differently. Currently, state law requires eligibility at 185% of the federal poverty level. The council agreed with the decision not to change the eligibility determination for farm and small business owners or to make any changes to the financial data form.

**High cost clients meeting $20,000 limit:** This year, there were no CSHS clients that are close to the $20,000 limit. There were a few that CSHS paid higher amounts for, such as $6,156, $5,034, $4,750, two that were over $3,000, and seven that were over $2,000. There is a family with two boys that have been diagnosed with Hypopituitarism who are receiving the prescription Omnitrope. Due to the high cost of this drug, CSHS staff will monitor these two cases closely. To date, CSHS has paid $5,625 and $6,846 so far, and their annual review is not due until 6/29/17. CSHS staff doesn’t foresee these cases reaching the $20,000 cap but it could be close if additional claims are submitted along with the prescriptions.

**Russell Silver Syndrome:** For the 2015-2017 biennium, of the four eligible clients, only two used the services last year. CSHS paid out a total of $8,822.17 for medications and travel for these individuals.

**Travel assistance for Medicaid-eligible children:** A trend that was noted when going through the division’s miscellaneous calls was inquiries for travel assistance for Medicaid-eligible children. As of 12/31/16, waivers such as the Developmental Disabilities Waiver and the Medically Fragile Waiver discontinued reimbursement for travel to families. The rationale for the change which was directed by the Centers for Medicare and Medicaid Services (CMS), was that transportation should be covered under the Medicaid state plan. Medicaid does provide transportation, but cannot directly reimburse families. If a family would like assistance with transportation, this needs to be arranged through their local county social services office. The provider offering the travel must be a ND Medicaid-approved provider.

**Diabetic Pumps:** CSHS is having some difficulties assisting with gap-filling for a few children needing diabetic pumps. Providers are referring families to durable medical equipment (DME) providers for diabetic pumps and supplies, but the DME providers are not enrolled with ND Medicaid, which affects CSHS’s ability to pay claims for the equipment/supplies. The two known DME providers that aren’t enrolled with ND Medicaid are Animas and Insulet Corp (Dexcom pump). The following are issues that this has caused:

- Claims are being denied because some DME providers are not enrolled in ND Medicaid.
- Claims are not being submitted to CSHS as the provider won’t bill a secondary insurance.
- Families have to pay a lot of out-of-pocket expenses.
Some things CSHS staff discovered while trying to resolve these issues are:

- DME providers have stated that they want to enroll with ND Medicaid but they aren’t able to due to ND’s laws and regulations.
- It is possible to have a local pharmacy order the supplies on behalf of the family and then submit the claim to CSHS, but only if the pharmacy is contracted with the DME provider. At this time, there are only four in the US that have a 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 these families.

The council discussed these issues and concluded that CSHS should conduct 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 council members as they are concluded. CSHS will bring forward information on state rules and regulations and revisit this issue at next year’s meeting.

Continuous glucose monitoring as a possible new standard of care: Dr. Connell disseminated journal articles about continuous glucose monitoring for the council to review. Dr. Sondrol supports patients using the devices but it works best for teenagers. For individuals that are younger, they aren’t always accurate. When the devices are used correctly, it could create cost savings in the long run. There was some discussion about the insurance coverage of continuous glucose monitoring. Different insurance companies make it difficult for families to obtain the devices. Continuous glucose monitoring should be recommended from a diabetologist. Dr. Quanrud motioned to work through this case by case. Dr. Carver seconded the motion. All were in favor. Motion carried.

Claims payment update with use of ND Health Enterprise MMIS: After go-live on 10/5/15, the ND Health Enterprise MMIS created some challenges, but since that time there’s been much improvement. CSHS staff were able to make connections with DHS and Xerox staff so as issues or questions arose, they were able to address them. CSHS is having issues with cost share clients; however, a solution is being worked on. The testing of the fix is set to be conducted at the end of May, and if it works, it will go into production on 6/9/17. Currently, CSHS staff are working on catching up on the back log of claims that are waiting to be processed. CSHS staff review and pay claims differently than ND Medicaid, as CSHS staff manually review each claim based on the child’s eligibility and diagnosis as coverage is based on CSHS policy. Claims are suspended and reviewed again during the payment cycle before finalizing the claim for payment. Due to the manual review of all claims, it takes more time to get through them. Over time, CSHS staff are becoming more efficient with the process.
Issues with claims processing are still being found, which is resulting in CSHS staff having to go back to the go-live date of 10/5/15, if necessary, to make those adjustments. The following are examples of why adjustments were needed: 1) the primary insurance information (EOB) was being applied incorrectly to the claims which resulted in incorrect paid amounts to providers and 2) there were also issues with how the reason/remark codes were being indicated on the provider remittance so the providers were not getting the correct information on how the claims were being processed. CSHS staff have fixed the errors and are working on doing the adjustments to correct any claims that were processed incorrectly.

**CSHS Policy Changes Effective 1/1/2017**

Cardiac Care for Children Program: Effective January 1, 2017, this program provides an initial examination by a participating pediatric cardiologist and routine tests for children with cardiac conditions in Bismarck, Fargo, Grand Forks and Minot. The program continues to ensure comprehensive and coordinated care through linkage and referral to other services and programs and through care coordination, as needed. Health care and financial information is available to families and professionals upon request.

Any child, birth to twenty-one years of age, who lives in North Dakota, may participate in this program. Third party payers, such as private insurance and Medicaid, are billed when available. If more extensive diagnostic services or treatment are needed, a separate application is recommended. To inform families and partners of the change in this program, the following actions were taken:

- A letter, which was copied to the appropriate county social services office, was mailed to families participating in the Cardiac Care for Children Program to notify them about upcoming program changes in October 2016. This letter was previously reviewed by the CSHS Family Advisory Council in September 2016 along with discussion of the Cardiac Quality Improvement Project.
- Program changes were mentioned at the training for county social service staff in October 2016.
- Sent e-mails and participated in conference calls with county directors and local staff in October and December 2016.
- Sent e-mails and participated in conference calls with family organization leaders in October and November 2016.
- Discussed program changes at a cardiac support group meeting in November 2016.
- Discussed program changes during Family Voices topical call in December 2016.
- Maintained a spreadsheet in CSHS to monitor enquiries from families.
- Followed-up with select county social service staff to assess impact with additional treatment applications.
- Sent Cardiac Care for Children program information to Cardiac Coordinators in December 2016.
- The programmatic changes were again discussed with the CSHS Family Advisory Council in January 2017.
- Letters were sent to participating pediatric cardiologists regarding Cardiac Care for Children Program changes in January 2017.

- A mailing went out 1/30/2017 to CSHS county social service staff, which included the following updates to the CSHS Policy, Procedure and Resource Manual: 1) Page 89-90, Cardiac Care for Children Program, 2) Appendix S – Cardiac Care for Children Program Registration Form, and 3) CSHS Diagnostic/Treatment Fact Sheet.
In February 2017, additional reminders were sent to the Cardiac Clinic Coordinators regarding how the Cardiac Care for Children Program should work, so that families were provided with the accurate paperwork at their appointments.

- Shared the list of CSHS County Workers with the Cardiac Clinic Coordinators in March 2017 so that families interested in applying for Treatment Services received the proper information.
- In April 2017, another mailing went out to the counties notifying them of the Poverty Level Changes that went into effect 5/1/17, along with the updated Diagnostic and Treatment Fact Sheet. This Fact Sheet was also updated on the CSHS website for convenience.

**Update on Diagnostic Program:** Effective January 1, 2017, Diagnostic services are used to secure a diagnosis when the diagnosis of a potentially eligible condition is unknown. Examinations can be covered until a decision about medical eligibility is reached. This program can no longer be used to “further the treatment plan,” since that left room for inconsistencies amongst clients and conditions. Clients still need to complete an annual review indicating that they need to continue services if their condition has not been confirmed or ruled out.

### CSHS Medical Eligibility/Medical Necessity

- **Septo-optic dysplasia:**
  Received a CSHS medical condition grid score of 19. This diagnosis is already covered under our CSHS-eligible diagnosis of “syndromes” so it does not need to be listed separately. Instead, it could be listed as an example of covered conditions under “syndromes”.

- **Vascular abnormalities, including aneurysms, arteriovenous malformation and moyamoya:**
  Received a CSHS medical condition grid score of 16. Dr. Shield motioned to approve adding vascular abnormalities to the covered condition list. Dr. Carver seconded the motion. All were in favor. Motion carried.

- **Infants with Hepatitis C:**
  Received a CSHS medical condition grid score of 14. This condition does not meet established criteria.

- **Autoimmune disorder:**
  Received a CSHS medical condition grid score of 16. Dr. Shield moved to approve adding Auto-Immune to the covered condition list. Dr. Carver seconded the motion. All were in favor. Motion carried.

- **Drug exposed infants:**
  Received a CSHS medical condition grid score of 13. This condition does not meet established criteria.
Coverage of secondary conditions as a complication of primary treatment condition: Complex medical conditions and their treatment can often result in complications which may be covered by CSHS on a case-by-case basis. If a child is already eligible for Treatment Services for a diagnosed condition, complications from that condition or from the treatment of the condition will also fall under Treatment Services. The following are examples of how this would be applied:

1. A child is on Treatment Services for a cardiac condition and takes a daily blood thinning medication. Labs to check clotting time would not be covered under Diagnostic Services, since the clotting issues are the result of the medication for which the child is already on Treatment Services.

2. A child is on Treatment Services for cancer, and the chemo regimen causes shortness of breath. The asthma medication to treat the breathing difficulties would also be covered under the Treatment Program, since this is the result of the primary condition’s treatment.

The council motioned and approved the coverage of secondary conditions as a complication of the primary treatment condition.

Autism Spectrum Disorder (ASD): Received a CSHS medical condition grid score of 17. At last year’s meeting, it was requested that CSHS obtain a cost estimate of ASD. According to Katherine Barchenger, the Autism Services Coordinator from DHS, the average cost per year per individual diagnosed with ASD under the waiver services is $22,190.

These services include the following:
- Service management
- Assistive technology
- Skills trainers
- Program design
- Monitoring and respite services

This estimate does not include the cost of therapies such as physical therapy, occupational therapy, and speech therapy. Therefore, even though ASD meets eligibility criteria, it would be too costly of a condition for CSHS to cover.

Discussion occurred on whether mental and behavioral health should be included on the medical conditions list and the costs associated with covering these conditions. In order to cover the costs of mental and behavioral health, other CSHS covered conditions would need to be eliminated.

It was requested that malocclusion (e.g., related to a condition or from trauma) be put on the agenda for next year. Dr. Feil may help devise a checklist.
Newborn Screening and the Metabolic Food Program

| Provision of metabolic formula for newborns without confirmatory testing: There were two cases this winter where the infants were presumptive positive for Phenylketonuria (PKU), but confirmatory testing took several weeks for confirmation. The CSHS Metabolic Manual indicates that “when the diagnosis is verified, a can of Phenex 1 is sent to the family or provider.” The following are recent examples of the waiting times for confirmatory testing:  
- One child was born in December 2016, and had a presumptive positive of PKU, but a diagnosis of true positive was not provided until March 2017.  
- A child was born in February and is still waiting for positive confirmation.  

CSHS staff do not want to withhold medical food during the waiting period. Since confirmatory testing has been taking several weeks before verifying a PKU diagnosis, CSHS staff and Dr. Connell determined that CSHS would provide metabolic food for infants for three months while waiting for the results. The council agreed with the decision to provide medical food for infants while waiting for PKU diagnoses.  

| Expanded Metabolic Food Program for males up to age 26 with PKU and MSUD without an appropriation: The council was provided a list of medical food (formula) that is available through CSHS. Between 2016 and 2017 formula prices have increased between 2% to over 11% depending on the company and the type of formula.  
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 also attended the conference to take advantage of cross-training and mentoring. Upon CSHS’s request, Dr. Breedon provided a presentation for the NDDoH and the metabolic clinic team to share new information gained from the conference.  

| Coverage of Hyperphe/PKU variant: Dr. Casas treats all children with metabolic food to keep their phe levels at 2-6. Dr. Casas indicated that the terminology used now is phenylalanine hydroxylase deficiency (PAH).  
- A question for the council is whether individuals with varying degrees of PAH be classified as having PKU and therefore eligible for no-cost metabolic food. Some of these children have been referred to as having hyperphe and have not been provided with the metabolic food unless their levels were greater than 12. Currently, there are two brothers that have hyperphe and their levels are greater than 9. Dr. Connell completed extensive research and conducted a telephone meeting with Dr. Kari Casas, CSHS, and Newborn Screening staff to discuss current practices of treating PKU with metabolic food. After the discussion, it was determined that best medical practice for treating PKU, PAH and hyperphe was to provide medical food for individuals to keep their phe levels in the desired range. It was determined that CSHS will provide formula based upon the diagnosis and recommendations of the treating specialist/physician for PKU, PAH and hyperphe. The council was informed of the discussions and final decision.  

Long-term follow-up continues as it has been done in the past. The infants that are presumptive positive for PKU have a longer follow-up process in order to ensure that they are being adequately served. They are able to get their medical food
(formula) through the Women, Infants, and Children (WIC) Program if they qualify for Early Intervention. Families are encouraged to utilize WIC for their formula needs, and then transfer to CSHS when they are no longer eligible for WIC services. Some families choose to receive their formula through CSHS instead of WIC, even if they are eligible for WIC services.

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<td>Early Hearing Detection and Intervention (EHDI): Christine Brigden, EHDI Follow-Up Coordinator, provided a summary of EDHI. In the past, EHDI’s mission has been to improve newborn screening rates and improve loss to follow-up. However, the new focus of the EHDI grant has been shifted to early identification/diagnosis of hearing loss in newborns, provision of care coordination and linkage to community resources like Early Intervention, options on tele-audiology to improve follow-up, and to move into more partnering with services like family support after the diagnosis. Dr. Nelson stated that tele-audiology is a nice option to be able to reach remote populations, but doesn’t replace an Ears Nose and Throat (ENT) or Audiology visit.</td>
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| Autism Spectrum Disorder (ASD) database update: After the ASD database went live on February 8, 2016, some mandatory reporters raised concerns of potential ethical violations. After working with staff in the Attorney General’s office, the attorney representing the ND DoH and the attorneys representing the mandatory reporter practice boards, it was decided that an advisory group meeting be held. A meeting of the ASD Database Advisory Group occurred on March 25, 2017. Each of the mandatory reporter practice boards and associations were asked to appoint a licensee to the advisory group. Family advocacy groups were asked to appoint an advocate/parent to participate in the advisory group as well. The following boards and associations had appointees represented in the advisory group:  
- ND Board of Counselor Examiners  
- ND Counseling Association  
- ND Marriage and Family Therapy Board  
- ND Nurse Practitioner Association  
- ND State Board of Psychologist Examiners  
- ND Psychological Association  
- ND Medical Association  
- ND Board of Social Work Examiners  
- Family Voices of ND  

The purpose of the meeting was to discuss reporting issues, the review and revision of the ASD report form (SFN 60804), and advice for provider outreach, education, and training. |

CSHS Clinics: CSHS is exploring electronic dissemination of the Clinic Directory.
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<th>Closing Remarks/Wrap-Up</th>
<th>Three council members had terms that expired this year. They included Dr. Nelson, Dr. Quanrud and Dr. Schield. All of the members whose terms were expiring agreed to commit to another two-year term.</th>
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<td>Dr. Connell closed the meeting after giving a warm thank you to the council for all their hard work and support.</td>
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