

Children's Special Health Services
 Medical Advisory Meeting
 May 3, 2014

Attendance:	
Appointed Medical Advisory Council members	Thomas Carver, DO; Sue K. Wink, MD; Ellen Feldman, MD (Skype); Blake Feil, DDS; Myra Quanrud, MD; and John Martsolf, MD
Children's Special Health Services (CSHS) Division staff	Tamara Gallup-Millner, Division Director; Devaiah Muccatira, SSDI Program Coordinator; Kim Hruby, Program Administrator; Tammie Johnson, Program Administrator; Tina Feigitsch, Claims Processing Specialist; Kodi Berg, Autism Database Administrator; Diane Bruley, Administrative Assistant; and Carrie Tate, Administrative Assistant
Continuous representation on the CSHS Medical Advisory Council	Julie Schwab, Medical Services Division Director, DHS; Courtney Koebele, North Dakota Medical Association; Gary Betting, MD, Medical Consultant, Medical Services; Melissa Schroeder, Family Advisory Council Designee; Cheryl Klee, Family Advisory Council Designee; and Joan Connell, MD, CSHS Medical Director.
Welcome and Introductions	<p>Tamara Gallup-Millner, Children's Special Health Services Division Director on behalf of Dr. Terry Dwelle, the State Health Officer, provided a warm welcome and relayed appreciation for the time everyone has devoted for this 61st Annual Medical Advisory Council meeting.</p> <p>Tammy continued by thanking members of the Medical Advisory Council who have staffed clinics, provided expert consultation when advice is needed, or have been involved with special projects over the year that improve the health and well-being of children and families in North Dakota. Tammy recognized the Family Advisory Council members that were able to attend. Dr. Connell recognized Dr. Martsolf, as this is his last meeting with the Medical Advisory Council.</p>
Health Department and CSHS Update	<p>Tamara Gallup-Millner relayed that CSHS currently functions with 9.1 full-time staff and the part-time services of Dr. Joan Connell, CSHS Medical Director. Since the last Medical Advisory Council meeting Carrie, Tina, and Kodi have joined the division.</p> <p>Tammy gave a brief overview of the budget for the 2013-2015 biennium, which includes spending authority for federal funds and matching general funds, is about \$3.0 million. The major federal funding sources for the division continue to be the Title V Maternal Child Health (MCH) Block Grant and the State Systems Development Grant. Uncertainties and timing of federal grant awards continue to be challenges with federal funding. Although federal MCH block grant awards have decreased by nearly 11% over the last decade, for the current FFY, the MCH Block Grant received a \$20,000 increase.</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.</p> <p>Tammy shared some programmatic highlights and reviewed handouts that were included in the meeting packet. The main focus of the Medical Advisory Council meeting is to obtain advice for the Specialty Care Diagnostic and Treatment Program. Direct services are one of our main functions in our division. The Legislature has mandated financial eligibility for</p>

CSHS at 185% of the Federal Poverty Level. This equates to about \$44,123 for a family of four. The only deduction allowed is annual health insurance premiums that are paid out-of-pocket.

Tammy reviewed the reports that were generated for the meeting.

- CSHS served about 2,100 children in 2013.
- The Medical Condition Report was included and showed the number of children in the database with CSHS eligible conditions.
- The health care coverage report shows that over 91% of the children served have a source of health care coverage. CSHS is a secondary payer that fills the gaps for what other payers do not cover. Over the last few years, we have seen a trend of a decrease in private insurance and an increase in Medicaid coverage for the children served through CSHS. It will be interesting to see the results of the Affordable Care Act and the Healthcare Marketplace and how it will affect families in our state.
- On the claims payment report, CSHS paid about \$175,000 in claims through Medicaid Management Information System (MMIS).
- Over 85% of all CSHS diagnostic and treatment expenditures were paid out for the following conditions:

Condition	Dollar Amount CSHS Paid	Kids with Claims Paid
Diabetes	\$44,935	27
Leukemia	\$28,662	3
Seizure Disorder	\$18,922	7
Cleft Lip/Palate	\$8,621	15
HC Malocclusion	\$7,911	5

Looking Forward – Opportunities and Challenges

Maternal and Child Health (MCH) Transformation 3.0: Tammy briefly discussed the significant transformation in the MCH block grant that is expected in 2015. The vision is to improve MCH by improving access, quality, integration, accountability, and equity. Aims are to reduce burden, maintain flexibility, and improve accountability. Significant changes in the state outcome and performance measures are expected. Some programmatic changes are anticipated to follow these federal changes which will affect the focus of ND’s future MCH work activities.

Collaborative Improvement & Innovation Network to Reduce Infant Mortality (COIIN): Tammy relayed that North Dakota will participate in a multistate summit this summer to expand the COIIN initiative into Region VIII. They will work on action plans to reduce infant mortality and disparities in birth outcomes using the science of quality improvement, collaborative learning and innovation to identify and share effective evidence-based approaches.

Affordable Care Act – the Healthcare Marketplace and Medicaid Expansion: Tammy spoke about the ACA and how it will continue to be important as CSHS moves forward. In North Dakota, 10,597 people signed up for private insurance in the Health Insurance Marketplace, many of whom were eligible to receive financial assistance for those plans. 19% of enrollees

	<p>were under the age of 18. CSHS expects to continue its gap-filling role. Families with children with special health care needs are especially concerned about habilitative coverage. Care coordination is also becoming more difficult when families have to navigate through differing coverage sources for various family members.</p> <p><u>Impact of technology changes (e.g., Electronic medical records and MMIS roll-out):</u> Tammy touched on some of the upcoming technology changes that CSHS is and will be experiencing. Electronic medical records (EMR), the health information technology challenges, trickles to our claims payments and has caused a backlog as these things roll out in the health systems. Medicaid management information system (MMIS) roll-out is tentatively scheduled for September 1, 2014 and there will be some challenges as that gets implemented this year.</p> <p><u>Interim legislative activity, potential legislation, and 2015-2017 budget:</u> Tammy gave a brief overview on some of the legislative activity that CSHS is involved with.</p> <ul style="list-style-type: none"> • CSHS has been involved in the Department of Human Services focus group for HB 1378, which is looking at how best to fill gaps in coverage for children who have substantial medical and support needs. Options include expanding federal poverty level (FPL) eligibility for the Children with Disabilities Buy-In program to 250-300% and revising the level of need assessment required with the Medicaid waiver for medically fragile. • Family organizations are interested in potential legislation for the upcoming session that will address the provision of information for prenatal and postnatal diagnosed health conditions. • Agency budgets will be developed this spring and summer in preparation for the 2015 legislative session. <p><u>New publications about children with special health care needs and their families in ND:</u> Tammy acknowledged that Devaiah has worked hard on developing new publications that document the needs of children with special health care needs and their families. Some of the publications were included in the packet and others are available online. A list of web links to these documents was provided.</p>
<p>Medical Services Update</p>	<p>Dr. Connell welcomed Julie Schwab, Director of the Medical Services Division in the North Dakota Department of Human Services who provided an update for council members. Julie continued the discussion on HB 1378. Back in 2013 the Department of Human Services was in charge of looking at the DD waiver and the issue of all the kids that were coming off of the waiver at age 3 but are still needing services, to see if there was something we could take a look at and put together for the next legislative session to be looking at what options there might be.</p> <p>Julie proceeded to read a paragraph that the legislature charged the department with. “The Department of Human Services, during the 2013-14 interim, shall identify the estimated cost to implement a Medicaid waiver or amend an existing Medicaid waiver, to provide coverage for children who have continued and substantial medical support needs, but who, at the age of three years, no longer qualify for services under the developmental disabilities waiver. In preparing the estimate, the department shall secure input from stakeholders, including families, providers, and advocates. The Department of Human Services shall report its findings to the 64th legislative assembly. The report shall include the estimated number of children eligible, criteria for the provision of services under the waiver, the services to be offered, and a timeline for implementation of the waiver.” Over the course of five meetings, this is what the department has been trying to do and one of the challenges is to identify the actual number of children that need this service. The focus and costs would include this number plus an</p>

	<p>additional 15 children over and above the number that are served currently. The next meeting will be to continue developing a screening tool and putting the financial information together.</p> <p>Tammy commented that families access the state plan services. In addition to the Medicaid state plan, there is an array of services depending on the type of waiver, families can also access for that eligible individual. It is a broader array of services.</p> <p>The Affordable Care Act (ACA) has impacted eligibility determination for children by using Modified Adjusted Gross Income (MAGI) methodology. Now children enrolled in Children’s Health Insurance Program (CHIP) whose income is below 133% of poverty level must be transferred from coverage through CHIP to coverage through Medicaid. The number of children within this group is 721.</p> <p>With this new methodology 3,196 that are no longer eligible for Medicaid were moved to CHIP for one year. This transition period started in April. Next April there will be children that will be able to continue to be on CHIP or if they no longer qualify for Medicaid or CHIP they will be directed to apply on the Healthcare.gov website to figure out where they can qualify. There is a lot of speculation about what is going to happen with CHIP. Continuation of the program will be a federal decision.</p> <p>Dr. Connell talked about the letters of support being sent to the governors to support the continuation of CHIP. Julie stated that there will be a meeting of governors that will be taking place to have a unified position to support the continuation of CHIP. Those that had the option to move to Medicaid did have the option to stay on CHIP for another year. Most will stay for that year because the coverage is better. Financial eligibility for CHIP is 175% the federal poverty level.</p> <p>In general for the adult population, it is projected that 20,000-30,000 adults between the ages of 19-65 could qualify for the expansion. The number that has applied and has qualified for Medicaid expansion is approximately around 7,500. One of the things that may drive this number up is that the hospitals want people to have coverage. They are working on hospitals being able to have the ability to have presumed eligibility determination if people appear eligible by income and family size for up to 2 months until they are determined ineligible. Working on their systems, and there is a form of about 10 questions, that they will fill out. Even if they are determined ineligible the facility will still get paid for that 2 month period of presumed eligibility. A person would only get one 2 month presumptive eligibility period per year. They would still have the option to fill out an application if income or situation changed. With this, if a person may be able to get coverage with the Marketplace or the Expansion, hospitals may not be as willing to work with people on payment options.</p>
Minutes	Dr. Connell asked if there were any comments regarding the 2013 minutes. Courtney Koebele moved to approve the 2013 minutes. Dr. Myra Quanrud seconded the motion and all were in favor. The minutes were approved.
Provider Qualifications, Certification, and Enrollment	<u>CSHS provider certification update:</u> Tina gave a brief overview that there were 158 specialists due for re-certification per the information in the database. Of these, 139 were verified and re-certified. Ten specialists have not recertified which include four family practice physicians, two internists, one occupational therapist, one speech/language pathologist, one pulmonologist, and one dentist. There were also nine specialists removed from the specialist list as their licenses were

	<p>expired and they have either relocated out-of-state or retired. Tina will be following up on those that did not recertify.</p> <p><u>Advice on CSHS provider-related issues</u></p> <p><u>Potential deletion of Prosthetists and Orthotists from the CSHS specialists list:</u> Kim started a brief discussion whether to remove these specialists from the list since CSHS does not receive any claims from them. The claims come in from the suppliers and not the specialists. Dr. Connell responded that there is a qualification list, but CSHS does not use this since the claims do not come from the specialist. Dr. Quanrud questioned if there was some qualification criteria for the suppliers. Kim responded that CSHS does have qualifying criteria for the suppliers and that they must be Medicaid enrolled in order for CSHS to make a payment. Dr. Quanrud would suggest taking the providers off of the list, since there is qualification criteria listed for the suppliers.</p> <p><u>Hospitalists:</u> CSHS staff questioned if Hospitalists should be added to the specialists list since a hospitalist is a specialist in another specialty. Dr. Connell stated for example if a child gets admitted to the hospital for an eligible reason, the patient does not get a choice of which hospitalist would care for them. Dr. Wink thought it would be redundant to add them to the list. Dr. Feil asked since a patient does not get a choice of who cares for them, is the hospital a provider, or what if the specialist is not on the CSHS list? Dr. Connell explained that this would be handled similar to an ER physician; since the patient does not get a choice CSHS would be able to cover it. Dr. Quanrud commented that FP's are also now working as hospitalists. Courtney Koebele asked how hard is it to apply to be on the list. Tina explained that she searches provider's credentials and submits that to Dr. Connell to be certified and then adds them to the list. If for some reason CSHS cannot find the credentials, Tina will contact the credentialing department. Tammy also commented that the vast majority of providers maintain their certification. Dr. Connell asked and everyone was okay with not adding hospitalists to the list. Overall consensus was to not add them to the list.</p> <p><u>Follow-up on prescriptive authority of PA's, NP's and CNS's:</u> Dr. Connell stated that there needs to be some relationship with the physician assistant (PA) and a physician, otherwise all of these providers have full prescriptive authority. CSHS wants to make sure that children with special health care needs have their needs met. As of now there are no concerns as claims are reviewed.</p>
<p>Newborn Screening and Follow-Up</p>	<p><u>Metabolic/Genetic</u></p> <p>Tammy discussed the information that was included in the packet regarding the draft 2013 ND newborn screening statistics.</p> <p><u>Newborn screening fee increase:</u> Tammy discussed the slight increase in fees on March 1, 2014 from \$60 to \$68.08 per baby. The fee covers the cost of courier services, lab fees, database fees for tracking and short-term follow-up services and medical consultation with our partners in Iowa. This fee is still very low compared to other states, and may continue to have an increase from year to year in order to continue to manage the system. If North Dakota decides to screen for additional conditions, another increase would have to be considered.</p> <p>Dr. Carver asked about the charges for repeat screenings. Kim responded that repeat screenings are covered under the DRG, unless it is done outpatient, then there will be separate charges for it. Iowa has been notifying CSHS of any abnormal screening results for ND babies. Within 7-10 days, Tammie Johnson contacts the family to help with</p>

coverage options for the additional testing and to provide care coordination. Melissa Schroeder asked if the family is contacted by the provider before Tammie talks to them. Kim commented that is why CSHS switched to the 7-10 days instead of 3 days, before contacting the family there are still rare instances that the provider has not contacted the family yet. Tammie continued the conversation stating that in emergent cases Iowa contacts the physician/hospital immediately and then the physician will almost immediately contact the family. Dr. Carver asked if additional testing is a covered service by CSHS. Kim answered that under the diagnostic program, all newborn screening conditions are covered conditions.

Upcoming administrative rule changes: Tammy touched on the complicated changes with state law and administrative rules. North Dakota partners with the state of Iowa, and it has been a good partnership. The Department of Health is looking at fees and how Iowa is paid, and the types of conditions that are screened. This does not necessarily need to be a legislative process each time a change needs to be done.

Metabolic clinic update: Tammie Johnson shared that Dr. Kenien was out for a while and was not able to attend some clinics. Dr. Casas helped fill in while he was gone. Dr. Kenien is back facilitating the Metabolic Clinics. There has been one clinic added on June 19, 2014 to allow for the added numbers of patients that want to be seen during the summer months.

Tammy commented that it is tough when one provider is unavailable, and that finding someone to cover was challenging, causing delays in clinics. Dr. Connell thought that CSHS should foster this interest, such as Dr. Casas, for those wanting to attend and help at clinics, especially when there are only a couple of providers in the state with that specialty. The majority of the council agreed that CSHS should foster this interest. Dr. Quanrud stated that backup is especially important during crisis situations. Dr. Martsolf asked if Dr. Casas will still be involved. Tammie replied that Dr. Casas would like to be and is interested, but it does not sound like she will be involved much at this time unless asked to. Dr. Carver added that Dr. Casas does a very nice job for families that he referred to her. Dr. Connell stated that any guidance or recommendations from the council on how to involve a new provider without devaluing a current would be helpful. There was no further discussion on this topic at this time.

Cost analysis for BetterMilk - a new formula for clients with PKU: Tammie discussed that two families have asked if CSHS would consider providing BetterMilk as a formula for those clients with PKU. The feedback is that it tastes better and can be used for cooking. She provided a handout of a cost analysis comparing BetterMilk with two other formulas which are frequently used and currently available through CSHS. The cost of BetterMilk is approximately 38% higher than the other formulas. The costs were broken down to daily and weekly costs, as well as cost per gram of protein equivalent. Is this something the council thinks that CSHS should have on its formulary? The supply company may consider a slight decrease in price, it is somewhat negotiable. WIC does not cover it and it is not on their list. WIC also stated that they would not consider it. Iowa also does not offer it on their formulary.

Discussion included: How is it guaranteed that the client receives the recommended full serving if it is used in cooking? Rice milk and almond milk can also be used for cooking for PKU. Has a study been done regarding patient

compliance with BetterMilk compared to other formulas? Tammie was not aware of any study being done. Could a voucher system be used? Tammy said this would require a change to ND Century Code.

The recommendation of the council was to ask the company that supplies BetterMilk to reduce to a price to equal the cost of other formulas (approximately \$150 per week). If the company agrees, CSHS could supply BetterMilk to their PKU clients. Dr. Quanrud motioned this and Dr. Wink seconded.

Early Hearing Detection and Intervention (EHDI)

Grants: The ND Center for Persons with Disabilities (NDCPD) received a federal Maternal and Child Health Bureau EHDI grant for the time period of 4/01/2011 through 3/31/2014.

- Although a formal notification of grant award has not been given yet, it was relayed at the National EHDI Conference that all applications have been fully funded for an additional 3 years.
- In ND, hearing screening is not state mandated.

NDCPD also received a Center for Disease Control and Prevention Early Hearing Detection and Intervention Information System (EHDI-IS) Surveillance Program grant for the time period 7/1/2011 through 6/30/2016.

The grants are intended to reduce loss to follow-up and enhance electronic system capacity to collect data, and to ensure children receive recommend screenings.

Data & Quality Improvement: EHDI still struggles with certain “population pockets” and loss to follow-up. EHDI will be attempting a Quality Improvement Project with the goal of collaboration with ND midwives.

- A CDC Survey based off 2012 data showed 87 babies missed their hearing screen completely.
 - In 2012, there were 67 home births reported in Oz.
 - These home births accounted for 67 of the 87 babies that missed their hearing screen.

AAP Chapter Champion: Dr. Kathy Anderson, Pediatrician from Mid Dakota Clinic in Bismarck, will be the AAP Chapter Champion for EHDI. Dr. Bernie Hogarth from Grand Forks was the previous Chapter Champion.

Upcoming Goals: ND EHDI will be restarting its EHDI Advisory Board, and hope to plan a meeting soon.

Dr. Quandrud asked if there is a geographic area in the state where the missed babies are. Kim responded that the Williston area is one, and some babies are getting discharged too early. Belcourt is another area where there have been some issues. EHDI hopes to get some representation from those areas. Dr. Connell also commented that there is no Right Track person currently in the Williston area. Kim also stated that North Dakota has about a 99% screening rate currently, which is really good compared to other states.

Critical Congenital Heart Disease (CCHD): Tammy would like some feedback from the council, in July 2013 the Department of Health sent out a screening mandate along with a memorandum addressing changes in the newborn

	<p>screening law that required the additional screening for heart defects. This memo included information on the CSHS Cardiac Care for Children Program. CSHS has no idea how this is going and it is up to the facilities to follow through on this.</p> <p>Dr. Quanrud stated that Jamestown has had three positive screens and they were able to be transferred to Fargo. Tammy asked the council if they think that the best practices protocols are being followed. Dr. Carver said that there is no way to track this, but they also are following the CDC protocols and getting kids screened, then getting those that have a positive screen connected with follow up testing right away. Melissa Schroeder said that with Family Voices, they are working with families with the available services for those going out of state, and helping them transition when they return home.</p>
<p>CSHS Medical Eligibility/Medical Necessity</p>	<p><u>Options and rationale for coverage of “select” equipment:</u> It has been discussed that CSHS currently does not have a distinct method to rationalize what would be covered or not when various requests come in for equipment. The drafted Medical Equipment Policy was disseminated to the council.</p> <p>Discussion included: Standing, hand braces/wrist braces might be something to add. Sleep apnea in children is on the rise and there are breathing issues along with that. Helmets for seizures. Tammy discussed that there have not been a lot of equipment requests. Also what thoughts are there for in iPad as a piece of equipment? iPhone have been used for communication purposes and some schools may supply an iPad for children. Tina said that we have not had any requests for an iPad as of now and if it was for a rehab issue it would be reviewed by Dr. Connell. Decisions on the equipment that would be listed would be reviewed by Dr. Connell and the administrative team in CSHS.</p> <p>Should we add standing braces, hand/wrist braces to the list? Kim said that CSHS has braces listed as a covered item under some qualifications, so it may be covered, just not under here. Dr. Connell feels that the braces should be added to the list. Dr. Betting also commented that the word “properly” should be looked at in the draft policy. A recommendation was made to refine the policy and then send a revised copy to Dr. Betting, Dr. Quanrud, and the Family Advisory Council to get feedback after the policy is refined.</p> <p><u>Review list of denied conditions for 2013:</u> The following are the list of denied conditions for 2013: Hydronephrosis – ineligible condition, Periodic Fever Syndrome – ineligible condition, GERD – ineligible condition, Hearing Loss – does not meet criteria for condition, Kidney Laceration – does not meet criteria for chronic condition, and Malocclusion – does not meet the point requirement.</p> <p>Dr. Quanrud questioned if GERD would ever be covered, in a severe case. She was not advocating, just curious. Dr. Connell responded that GERD sometimes does not meet the chronic component. There were no other thoughts from council members.</p> <p><u>Housekeeping changes to medical condition list:</u> Transverse myelitis was added. Changed some terminology and included layman’s terms for accessibility and usability for most. Dr. Feil commented that only one cause was listed for sleep apnea, some are temporary, but usually would have surgery. Dr. Connell stated that one of her concerns about adding sleep apnea in</p>

	<p>a broader way to the condition list is most obstructive sleep apnea is fixed when tonsils are removed, and CSHS does not cover a tonsillectomy. Dr. Quandrud commented that central sleep apnea as well as obstructed sleep apnea, other than the tonsils or adenoids, should be added. Dr. Wink also commented that it is not chronic if the tonsils are removed. Dr. Quanrud asked why tonsillar hypertrophy was not on the list and adenoid hypertrophy was. Dr. Connell agreed and was not sure why it is not. Dr. Feil also stated that it is important that sleep apnea is verified by a sleep study. Dr. Betting said this could be done with overnight pulse oximetry. Dr. Carver asked about feedings and equipment for kids that cannot swallow. Kim stated that this would be considered under GI abnormalities possibly or Dr. Connell said possibly would be under diagnostic, but it would not cover feedings, the feedings would be under the treatment program. Suggestion was made to possibly add obstructive sleep apnea.</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 three children who were monitored for possible high dollar payments this year. 1) 20-year-old with Seizure Disorder no primary insurance coverage for needed medication. As of April, almost \$17,000 has been paid out. Financial Review is due in May 2014. Likely will not exceed \$20,000. CSHS staff have been monitoring amount paid out very closely and keeping family & county informed. 2) 17-year-old with a heart condition, no primary insurance. Had a heart ablation procedure out of state, high recipient liability but still reached almost \$17,000 so far but no other major bills are expected. 3) 20-year-old with cleft, no primary insurance. Had surgery in-state, inpatient hospital stay and reached about \$8600.</p> <p>In the last five years, there have been only two children who reached the limit. One child had cancer and maxed out in 2009. The other child had a cardiac condition and maxed out in 2011. CSHS was the child's only source of coverage. The child 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 the family 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. One child who has a seizure disorder has been a high cost, but has not reached the max yet. This child is covered under Caring for Children, but it does not cover medications. Thus, CSHS is acting as a gap filler, covering the medications.</p> <p><u>Update children served with Russell Silver Syndrome:</u> Kim discussed the general funds budget for the entire program is \$75,000 with a maximum \$50,000/per year, per child. The program currently has five children enrolled, and until recently only two children had claims that CSHS paid due to Early Invention covering them until they are three years old. There has been only one concern over the year with costs. One had their primary insurance deny coverage for one month of medication, and CSHS had to cover medications and be a gap filler for that month. Tammy mentioned that her concern in this area is that the legislature decreased the funding to \$75,000 total for the entire program, and with kids who will be coming off of Early Intervention, there may be an elevated need for the funding.</p> <p><u>Pacemaker checks – coverage under Diagnostic or Treatment Program:</u> Kim explained that CSHS is questioning if pacemaker checks should be covered under the Diagnostic Program, Treatment Program, or Cardiac Care for Children Program. Currently it covers pacemaker checks under the Diagnostic Program, if CSHS did not pay for the placement of the pacemaker. This dates back to a decision point from 2009. Unfortunately, there is not much rationale available regarding the history of this decision.</p>

Dr. Connell stated that a pacemaker placement would be under treatment. Would a pacemaker check be similar to a treatment issue? Kim said that we have three options: 1) Continue what is currently being done and cover the checks under diagnostic, 2) cover it under the Cardiac Care for Children Program, or 3) move it under treatment services which would require income eligibility.

Discussion included: CSHS is trying to make this fair for all kids. A few responded that if they are under the Cardiac Care program shouldn't it be covered under that, or that it should be under the treatment program. Tammy responded that CSHS are very specific about what we cover under the Cardiac Care for Children Program. Dr. Connell added that the Cardiac Care for Children covers more of what is done on a generic cardiac check; a pacemaker check is not part of a generic check. Would kids being moved to the treatment program, be able to afford to pay for this? Approximately 91% of CSHS children are covered under insurance so most likely the family would be able to pay for it, there is the possibility that some would not. Melissa Schroeder responded that as a parent it is nice to have things transparent and consistent. She read the meaning of diagnostic and treatment: diagnostic is performing diagnostic tests to follow up on a risk that is identified and treatment is to control, correct, or reduce a health problem found. With this information the overall consensus of the council is to move pacemaker checks to the treatment program.

Medicaid gap filling and care coordination by CSHS - Case situations:

- 1) Payment for repeat echoes out of state: A child on a waiver and saw a cardiologist in ND where they did an evaluation and an echo was done. The ND cardiologist put in his notes that since the child would be following up with a multidisciplinary team out of state that the patient should have a repeat echo done at the out of state facility. The family followed up on this, Medicaid denied this due to services being available within ND. Due to the ND cardiologist stating that he would have a repeat echo out of state, CSHS did not feel that it was the family's responsibility to pay for something that was recommended. CSHS decided to cover it.
 - Should CSHS have sided with Medicaid, since the child technically could have had a repeat echo done in ND before traveling out of state? Or, does the council agree with the decision that was made?

Melissa Schroeder asked if Medicaid approved the out of state visit. Kim said that they did approve the visit, and denied the echo. Dr. Quanrud asked if cardiology was part of the out of state visit. Dr. Connell stated that she thought the mom wanted a second opinion, and then they had the echo, and mom said she didn't get the denial letter before they left. By the date on the denial letter, it was possible it was not received beforehand. Dr. Betting asked if CSHS can pay any provider. Dr. Connell responded that yes we can pay any providers. Courtney Koebele agreed that CSHS did the right thing with the decision that was made.

- 2) Specialized bottles for babies with cleft lip and/palate: Specialized bottles for cleft lip and palate are often medically necessary for feeding. ND Medicaid currently does not have a formal policy regarding the coverage of specialized bottles; they typically will approve 6 nipples if gone through appropriate prior authorization. CSHS had one circumstance with a child with a cleft with a strong suck that was wearing out his nipples more often than usual. Since Medicaid typically only allows 6 nipples, the family needed to submit additional paperwork for additional

authorization. This was very difficult and complicated for the family, who was just trying to do the best for their child's health.

- In these circumstances, CSHS has decided to help cover services such as these, as long as all other options for coverage has been explored (e.g., Family Subsidy through Infant development).

Council opinion/guidance – they seem to agree with CSHS's decision.

- 3) Hearing loss: Medicaid requires a 40 dB hearing loss in the best ear and CSHS requires a 20-30 dB hearing loss in one ear.

Dr. Wink said that 20-30 dB is a big difference in kids, unilaterally. Dr. Betting said this should be more specific on age (e.g. there is a difference of average hearing loss with a child that is one year old compared to a child that is 16 years old. Dr. Connell stated that CSHS may want to add age constraints and if this applies to one ear vs. two. Dr. Betting said that if one ear is normal the child does not qualify for hearing aids no matter what the other ear is. Tammy stated that we would like to keep in touch on this topic and talking with Dr. Betting on any Medicaid changes, as they are meeting with audiologists to consider changes to their policy.

- 4) Orthodontia: Gap filling with orthodontia. CSHS has been gap filling, since many orthodontists are enrolled in Medicaid but may not be taking new clients or may not be accepting Medicaid and have not closed their enrollment status. CSHS will cover these clients if they cannot find a provider that will take Medicaid.

New CSHS diagnostic re-evaluation process: CSHS has wished to implement a more formal process regarding the Diagnostic Program, which helps cover the cost of diagnostic services without charge to families for children who have, or are believed to have, a condition on the CSHS Medical Condition List. A summary of the new process was disseminated.

After doing a thorough review of all CSHS Diagnostic Cases, the following trends were found:

- Several children have qualified for Medical Assistance and would no longer need CSHS Diagnostic Services.
- Several children were over 21 years of age, which disqualified them from receiving CSHS Services.
- Numerous clients were only opened for one-time cardiac testing and can now be better served through the Cardiac Care for Children program.
- Many cases had conditions where the diagnosis was confirmed or ruled out, therefore no longer needing Diagnostic services.

Implementing a new policy should offer the following benefits:

- An annual re-evaluation will ensure that only active cases are left open.
- County workers will not need to keep files on clients who are not using services.
- CSHS will be able to accurately reflect how many clients are being served.

Selected Programmatic Updates

Autism

Database: Tammy mentioned that House Bill 1038 was passed during the 2013 session. Kodi discussed learning about Autism and the change from the DSM-IV to DSM-V and looking at other state registries that are already in existence. The HB 1038 is requiring the Department of Health (DOH) to establish an Autism Spectrum Disorder (ASD) database/ or registry which must include a record of all reported cases of ASD in the state of North Dakota, along with any other information determined relevant and appropriate by the department in order to complete epidemiologic surveys, enable research and analysis, and provide services to individuals with ASD.

- The bill also required the Department of Human Services (DHS) to establish an ASD voucher pilot program to assist in funding and educational needs. The DHS will collaborate with DOH to implement a training program for medical and behavioral providers, educational staff, child care providers, and parents.
- The DOH needs to establish criteria regarding who is qualified to report a case of ASD into the database.
 - Reporter must be a doctoral level professional, appropriately licensed, credentialed, and experienced with ASD including, intellectual testing and other evidence based assessments.
 - The department will consult with experts in establishing this criteria
- The database must include reported individuals diagnosed with ASD according to the most recent DSM manual, the DSM-V.
 - The individual must have a complete physical evaluation by a licensed physician
- The DOH needs to adapt administrative rules regarding the mandatory reporting to the ASD database, including timeliness requirements
- The DOH will keep confidential records.

Tammy stated that the legislature determined the “what’s” and now CSHS is working on the “how’s”. Input is needed from the council on who can report and what should be collected. DSM-V is a challenge because it is new and not everyone uses it. What is the best way to start moving forward?

Discussion included: Most are using the DSM-V, but it does not represent everyone, since some do not use the DSM. Reviewing other databases, such as Washington or New Jersey’s was suggested. It is unsure what criteria is used for those that are educational diagnosed and are not backed up by a medical diagnosis. There was no consistent way to diagnose across the country, the DSM-V was intended to make the diagnosis process less cumbersome, and psychiatrists are familiar with the DSM. Is the physical part to rule out, or is this not true? The law is not specific to rule out a physical exam. There are no criteria in a physical exam that rules out autism, the only reason for a physical exam is for something other than autism or to rule out other causes. A physical exam may pick up other things that may go along with autism, such as seizure disorders or other syndromes, etc. A team approach would be a gold standard from the psychologist for diagnosis. Typically to diagnosis depends on a psychologist, a psychiatrist can do a screen. Can any psychologist make a diagnosis or would it need to be a child psychologist? Any psychologist that has been trained, but a child would typically go to a child psychologist, PhD level. A trans-disciplinary team may be used. There is a team clinic currently that is not funded and they cannot bill all on the same day individually as providers, they have tried talking with the state for a year now and have not received any response. Trinity is looking at putting together a team and MSU has a team but has a backlog and is funded through the state. The reimbursement now is

actually pretty good for telemedicine, maybe this could be an option for billing purposes with the clinic team that is not funded. The problem is that there is no billing code that the clinic can use for the billing for each provider. Also, another frustration is if a child has a diagnosis, and applies for the waiver, they must have the waiver team diagnosis; which in North Dakota is currently either done by Dr. Quanrud's team clinic or the MSU team.

Tammy asked if anyone would be interested in participation in this expert panel or being a resource for CSHS. Dr. Quanrud replied yes to participating in the expert panel and being a resource for CSHS. Dr. Feldman said yes to being a resource and possibly on the expert panel.

Task Force: The autism state task force was formed in 2009, and contains representation from various state agencies, organizations, and family members. These members have been appointed by the ND Governor. The task force meets quarterly to discuss that state of the state, and also to create a state plan based on the identified needs.

Currently, the autism state task force is working to create a new state plan. The new state plan will be modified based on changes such as the most recent legislative rulings, the conversion from the DSM IV to the DSM V, the changes in the diagnostic teams, etc. The next meeting will be held on June 30, 2014. Meetings are open to the public and the information is available on the Department of Human Services website.

Supporting Autism in ND grant (SAND): The SAND grant has been doing outreach trainings to child care providers and medical offices. These have been focused on recognizing signs of autism as well as proper trainings for diagnostic teams surrounding autism.

This grant will be ending in the fall, and all work items will be able to be found on the new autism state website through the ND Department of Human Services. <http://www.nd.gov/dhs/autism/>

Upcoming Autism Conference: The first Autism State Conference and will be held October 20-22 at the Ramada Inn in Bismarck, next year it will be held in Fargo. There will be various tracks at the conference, including one for parents, providers, education, medical professionals, first responders, and ASD basics. CME's and CEU's are being applied for.

Kim thanked Dr. Quanrud and Dr. Carver who agreed to be on the resources in ND panel presentation. There will be information on evidence based practice with a professional coming out of Connecticut to do a presentation, Dr. Kathy Breedon from Sanford Fargo is going to come and discuss children with autism and nutrition, panel presentation on ND resources, medical home presentation, and a collaboration presentation about ND and New Jersey autism registries. New Jersey also offered to help guide Kodi on getting started with our registry. New Jersey did the same thing in Minnesota in helping get their registry started.

Courtney Koebele requested information on this conference; also send any information to the NDAAP. Dr. Feldman asked if any kids with autism are coming to present. Kim responded that some parents are coming to speak, but was not sure if the kids will be there to speak as well.

ASD Resource Booklet: The SAND grant has also been able to help update the CSHS Autism Resource Booklet. New standards regarding evidence based interventions, as well as updated resources can be found in the newest version. The booklet is in the final review process and will be sent to professional printing within the next few weeks. Dr. Connell stated that she also had some changes from the NDAAP meeting for the booklet, and those changes will be incorporated as well before it is sent to the DOH public information officer for review.

Multidisciplinary Clinics

Cleft clinic update: Kim thanked the providers who were present that currently devote their time to CSHS clinics. In addition, she thanked Dr. Feil for providing various items, such as specialized bottles, that have been included in the newborn gift boxes for children with cleft lip and palate. This was achieved through a fundraiser done last summer. The families have greatly appreciated it!

The cleft lip and palate clinics are held in four major hubs of the state: Minot, Bismarck, Grand Forks, and Fargo. Some interesting challenges that CSHS has faced throughout the year are:

- A political challenge of competing facilities sometimes makes decisions difficult for families. We want to ensure that families are given ALL options so that they can make an informed decision. The ultimate goal is to not have competition between medical providers be a determining factor in the child's choices of care. (e.g. certain doctors not referring to others due to competition and certain providers not accepting Medicaid)
- Although the honorarium that is currently offered to providers is not large, CSHS relies greatly on the providers' consistent attendance at the clinics to assess these children. Certain areas of the state struggle with provider attendance on a frequent basis.
- Due to high numbers of children being seen, an additional clinic has been added to the Bismarck location. This is difficult for scheduling, but will hopefully make the clinic day less chaotic. If this additional clinic goes well, another additional clinic may need to be added in the near future.

Tammie shared that she covers the clinics for the eastern part of the state, Grand Forks and Fargo. The biggest stumbling block would be providers who do not accept Medicaid. CSHS does its best to get the families connected with providers that do accept Medicaid, but some of the providers on the team do not accept it in their clinics and this can be confusing to families. Another challenge is kids that travel to the clinics from out of state, Minnesota or South Dakota, and not knowing the services that are available in those states.

Dr. Wink commented that she did not understand how a provider could be associated with a cleft palate clinic and not accept Medicaid. Dr. Connell asked if it should be a policy that the providers at the clinic accept Medicaid. Kim stated that we may not necessarily be able to do that when only one provider in a specialty is willing to provide outreach to certain clinics, and does not accept Medicaid. Then we need to make it aware to the family that if that is a provider they choose to go to outside of the clinic that the provider does not accept Medicaid and give them their other options in the state. Extra care coordination is required. Tammie commented that we want to be able to have that discipline at the clinic.

	<p><u>Contract update:</u> CSHS has 16 contracts that are currently funded, 15 service contracts and 1 admin contract for Dr. Connell for about \$450,000 a biennium. Projects funded include multidisciplinary clinics, care coordination services, family support services, and medical home initiatives.</p> <p><u>Reimbursement:</u> Tammie briefly brought up that one of the pushes is that the clinics start to receive reimbursement or that we at least look into this. The metabolic clinic at Sanford in Fargo does receive partial reimbursement and the rest of the team receives honorariums. Tammy added that there is a learning curve on how to get reimbursement, and we are currently looking into more information on this.</p> <p><u>Information Resource Center:</u> CSHS staff tries to develop one new resource booklet per year and found it needed to provide more information regarding complex dental conditions. A draft was distributed in the packets and the first draft was also reviewed by Dr. Goebel, Dr. Lugar and Dr. Feil. Some feedback received was to not use complex terminology such as “dental caries” or “periodontal disease”, as it can be confusing, and to use verbiage such as “decay” and “gum disease” instead. Another suggestion was to make more reference to the importance of a dental home, since there is reference given to medical home. The council was asked to provide any other comments or suggestions.</p> <p><u>Care Coordination</u></p> <p><u>State, local and contract staff:</u> Tammie talked about the continued state-wide care coordination that is provided, along with assistance to the local county social service offices. CSHS is starting to plan for their yearly County Training event, and a site review is scheduled for the Grand Forks Public Health Care Coordination Program on May 6, 2014.</p> <p><u>Medical home education in ND:</u> Handouts for the “Fundamentals of Medical Home for children and youth with special health care needs” were distributed. It is a self-study online course offered by NDCPD. The course will acquaint learners with the basic components of medical home systems and coordinated care for CSHCN. CEU’s are available for it.</p> <p>Dr. Carver commented that nurses in the office enjoyed the online course. Tammy stated that they are working on updating this curriculum.</p>
Closing Remarks/Wrap-UP	<p>Seven council members have terms that will be expiring this year. They include Dr. Carver, Dr. Goldstein, Dr. Quisno, Dr. Kenien, Dr. Feil, Lea Floberg and Dr. Martsof. Dr. Carver, Dr. Goldstein, Dr. Quisno and Dr. Feil have agreed to another term. Dr. Kenien and Dr. Martsof said no to another term. Dr. Martsof recommended Dr. Casas to the team and there is also Dr. Anju Sukumaran, who is a Pediatric endocrinologist in Fargo. Lea Floberg will be contacted to determine her interest.</p> <p>Dr. Connell closed the meeting after giving a warm thank you to the council for all their hard work and support.</p>