

Children's Special Health Services (CSHS) Medical Advisory Council Meeting

**Comfort Suites – Meeting Room A
Saturday – May 5, 2012
8:30 a.m. to 12:00 noon CDT**

Present from the Children's Special Health Services Division (CSHS), North Dakota Department of Health (DoH): Tamara Gallup-Millner, Division Director; Devaiah Muccatira, SSDI Program Coordinator; Sue Burns, Program Administrator; Melissa Evans, Eligibility & Claims Administrator; Diane Bruley, Administrative Assistant; Kim Hrubby, Program Administrator; and Brittany Getz, Administrative Assistant.

Present as Appointed Medical Advisory Council Members: Thomas Carver, DO; Heidi Goldstein, MD; Marcus Fiechtner, MD; Ellen Feldman, MD; and John Martsof, MD.

Present as Continuous Representation on the CSHS Medical Advisory Council: Maggie Anderson, Director, Medical Services Division, North Dakota Department of Human Services (DHS); John Baird, MD, Special Populations Section Chief, DoH; Courtney Koebele, North Dakota Medical Association; Gary Betting, MD, Medical Services Division Medical Consultant, DHS; Lori Hanson, Family Advisory Council Designee; Cheryl Klee, Family Advisory Council Designee; and Joan Connell, MD, CSHS Medical Director.

Present as Guest: Angela Richter, North Dakota Center for Persons with Disabilities.

WELCOME AND INTRODUCTIONS

Tamara Gallup-Millner gave a warm welcome and thanked the Medical Advisory Council members for their assistance during the past year. Introductions were made and the agenda reviewed.

OPENING REMARKS

Dr. John Baird, the Special Populations Section Chief, welcomed the Medical Advisory Council. Dr. Terry Dwelle, the State Health Officer, is in Taiwan. Dr. Baird discussed public health's role in prevention. Public Health is about assessing the health of our children and assuring that we are finding the children with special health care needs early. He also shared examples of public health success such as immunizations, clean water, and treating diseases early with newborn screening.

CSHS DIVISION OVERVIEW AND UPDATE

Tamara Gallup-Millner relayed that CSHS functions with eight full-time staff and the part-time services of Dr. Joan Connell, CSHS Medical Director. Tammy relayed that the CSHS Division's budget for the 2011-2013 biennium, which includes a combination of federal and state matching funds, is about \$2.8 million. The major federal funding source for the division continues to be the Title V MCH Block Grant, which has been flat funded for several years. The governor requested agencies submit a flat budget in addition to a budget with a 3% reduction. In light of this funding environment, CSHS has not made any significant changes in staff or services.

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.

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. This program helps families pay for medical services for eligible children. The Legislature mandated financial eligibility for the CSHS Treatment Program at 185% of the Federal Poverty Level. That equates to a family income of \$42,648, a year 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 serves around 2,400 children each year. The top conditions identified in children served through CSHS include heart conditions, cleft lip and/or palate, asthma, diabetes, and handicapping malocclusion. Last year, ninety-two percent of the children had a source of health care coverage. The majority were privately insured while others were covered by public insurance programs such as Medicaid or the Children's Health Insurance Program (CHIP), also known as Healthy Steps. Over the last few years, CSHS has seen a trend of decreasing private insurance and increasing Medicaid coverage for the children served through CSHS. Few changes are apparent in other coverage sources. CSHS continues to gap fill for the underinsured population. In regards to claims, the amount paid out for CSHS-covered conditions varied by type of condition. Total claims paid out by CSHS through MMIS were close to \$250,000. A decrease has been noted in claims for Russell Silver Syndrome and an increase has been noted in claims paid for the Cardiac Care for Children Program. CSHS payments through the Diagnostic and Treatment Program by condition ranged from a low of \$0 to a high of almost \$77,000. Ninety-one percent of the Diagnostic and Treatment program claims were paid for the following six conditions: handicapping malocclusion (40%), diabetes, which has seen an increase in the use of insulin pumps (22%), heart conditions (12%), cleft lip/palate (8%), hearing loss (4%), and asthma (4%).

MEDICAL SERVICES UPDATE

Tammy welcomed Maggie Anderson, Director of the Medical Services Division in the North Dakota Department of Human Services who provided an update for council members.

Maggie disseminated some handouts. She relayed that part of health care reform has been implemented. In October 2010 the correct coding initiative was implemented. All professional claims go through the correct coding initiative edit system, which is going well so far. The intent was to get claims paid correctly. In March 2012 the provider preventable condition edits and hospital acquired condition edits were implemented using the same policies as Medicare. The hospital acquired edit looks for conditions that are acquired as part of a hospital stay. If this happens, the payment is reduced. These edits have been newly mandated for Medicaid programs but Medicare has been using them for awhile.

Program Integrity for Healthy Steps and Medicaid has an audit system in place called Payment Error Rate Measurement (PERM), which is required by the Centers for Medicaid and Medicare (CMS). Auditors come through and audit claims payment, medical records, and eligibility. States are audited on a three-year cycle. North Dakota has done fairly well with this audit. ND Medicaid has also hired a Recovery Audit contractor. Significant changes have occurred with the provider enrollment system within MMIS, which began in 1978. Medicaid is in the process of doing provider enrollment cleanup. Some providers have never updated their information since they were first enrolled. Health Care

Reform will require that all providers re-enroll every three years. Medicaid will be hiring a vendor to make sure there is a match to the NPI number.

Maggie distributed a handout on their new out-of-state policy, which was effective March 1, 2012. This new policy is not intended to be used for all out of state services for children. Rather, it is intended to be used for specific cases and situations that require a broader application of “unavailable”. At least one of the four criteria must be met in order for the out-of -state request to be approved:

- To ensure continuity of care, and if the in-state referring provider has determined that the follow-up should be provided at the facility that performed the surgery or services; a follow-up to a previously approved and performed out-of-state surgery or specialty service.
- A set of inter-dependent services for diagnosis and treatment is needed and the entire set of services is not available in the state.
- After the in-state referring provider consults with the in-state specialist, it is determined that the wait time for in-state specialty services is expected to negatively impact the diagnosis or treatment.
- Only one in-state specialist is available to provide the service; however, adverse previous client or referring provider experience with the specialist substantiates the need to seek services out-of-state.

If the referring provider says that one of the criteria fits, then it goes to Medicaid for approval for medical necessity. Dr. Goldstein asked if there was a definition for adverse experience. Maggie stated that there was not. The family would need to explain the adverse experience and a determination would be made at that point. Two requests have been completed using adverse experience as the criteria. One was approved and one was denied. This policy will be trialed for six months. Medicaid still has their existing out-of-state policy. This new policy is to be used when the provider believes the typical out-of state request will be denied. Medicaid sent letters to all pediatricians, family practice doctors, and nurse practitioners to notify them of this policy. The documents are available on Medicaid’s website and the form is available on the State’s e-forms website. The referral has to come from the primary care doctor.

Maggie passed around another handout about the outreach that is being conducted. The intent of doing the outreach is so those who are potentially eligible know services are available. If the families are not eligible for Medicaid or the Children’s Health Insurance Program (CHIP)/Healthy Steps they are referred to the Caring for Children program and CSHS, if needed. Medicaid has seen an increase in enrollment because of the outreach. Dr. Fiechtner stated that reservations don’t know about Healthy Steps and that there is no outreach there. Dakota Medical Foundation contracted with KAT Communications and they are rolling out a large campaign to reach the American Indian population. There is a current misconception that if they sign up for CHIP then they can’t go to the Indian Health Service (IHS). The Tribal Chairman Health Board and IHS administrative staff are meeting quarterly with DHS. Maggie said that they aren’t seeing increased enrollment in oil country. They are trying to work with CMS on flexibility to see if they should enlist some benchmarks due to limited access to primary care physicians in that area.

Planning for Medicaid expansion is going forward with a January 2014 effective date. It’s the largest expansion since 1965 when Medicaid was started. In 2014, the categories will go away which will allow childless adults that are not disabled to be eligible if they meet the income guidelines at 138% of the federal poverty level. Medicaid is expecting a 50 percent increase in Medicaid eligibles. Currently, there are 66,000 individuals on Medicaid. Enrollment will start in October 2013. The number could possibly increase to 100,000. Medicaid must include the amount of funding needed to implement this change in its 2013-2015 budget.

Under health care reform, states are required to participate in health insurance exchanges. Rather than adopting its own, ND will participate in the federal exchange. A new eligibility system is being developed that will be seamless with the exchange.

Medicaid continues to work on the new MMIS system. It was supposed to go live in July 2009. The vendor has had delays in the core system. New Hampshire's new MMIS operations system will be first to go live with a projected start date of late 2012. ND is negotiating on contract amendments and is planning for the new MMIS system in October 2013. ICD-10 coding was due to be implemented in October 2013. It will require about 5-6 months of user testing before implementing, but the new system will be ICD-10 compliant. The Department of Health and Human Services announced possible delay of ICD-10 to October of 2014 but ND Dept of Human Services is still planning for an October 2013 start date.

BUSINESS

Minutes

Dr. Connell asked if there were any comments or questions regarding the 2011 minutes. Dr. Fiechtner moved to approve the 2011 meeting minutes. Dr. Martsolf seconded the motion and all were in favor. The minutes were approved.

Newborn Screening

Severe Combined Immune Deficiency (SCID) pilot

The addition of SCID to the newborn screening panel is still being reviewed in ND. Iowa, our newborn screening partner state, may be conducting a pilot program. There is no FDA approved screening kit for SCID. Iowa's pilot was intended to start in July but may be delayed. The SCID testing also picks up a lot of other disorders (e.g., autoimmune, some cardiac and thyroid disorders, 22q deletion, etc.) so other types of follow-up may be needed. ND will need to weigh the cost of picking up other conditions when considering screening for SCID. The prevalence for SCID is 1 in 137,000. The Department of Health is going to start an ad hoc committee to discuss the implementation in ND and determine if it is cost effective to screen if enough of the other conditions that presented as a presumptive positive are identified. Dr. Fiechtner recommended that the state wait until Iowa completes their pilot. The addition of SCID would add cost to the newborn screening fee.

Critical Congenital Heart Disease (CCHD)

In spring 2011 the Advisory Committee on Heritable Disorders in Newborns and Children recommended adding CCHD to the core panel for universal screening of all newborns in the United States. It took until fall 2011 for Kathleen Sebelius, U.S. Secretary of Health and Human Services to endorse the screening. The process to conduct CCHD screening is more like a hearing screening than the lab test used for other metabolic disorders. The protocol for follow-up is different than that used for blood spot screening. A survey has been sent to ND health providers to see if they are screening for this condition now. The data will be compiled and analyzed in the next month or two. One question on the survey asked if rural hospitals have the ability to do the pulse oximetry and echocardiograms on infants. Dr. Carver stated that it is important to screen for hypoplastic left heart because it doesn't show up until after the ductus closes, which is three to four days after birth and the child is at home. It has been estimated that the screening will take five minutes, but it will likely take longer. If there is an issue, it needs to be addressed before discharge. However, if a rural community doesn't have a pediatric cardiologist, that could be a problem. There's more follow-up needed for critical congenital heart disease so this can't be categorized the same as existing newborn screening. Dr. Martsolf said we need to have the ability to follow-up and have programs in place. Dr. Carver stated that screening would be a good idea if they are screening for conditions that can be treated.

If ND were to move forward with CCHD screening, it would need to develop a program that included funding, a screening coordinator, a standardized protocol with pediatric cardiology consultation, a data system to collect screening results and needed diagnostic follow-up, and information/resources to educate families and providers.

CSHS sees a lot of children with heart conditions but the addition of CCHD screening will likely have an impact on CSHS since more children would need diagnostic testing and potential treatment services.

Dr. Carver motioned to include CCHD screening once the tracking pieces are in place and to wait with SCID to see how things go in Iowa first. Dr. Fiechtner seconded this motion. Motion carried.

Early Hearing Detection and Intervention (EHDI)

EHDI started as a universal screening program in 2000 and was expanded to include follow-up/intervention. The North Dakota Center for Persons with Disabilities is the holder of both grants that fund ND EHDI. The HRSA grant funding is used to reduce the number of kids lost to follow-up. The funding goes through March 2013. The CDC grant is for data integration and tracking systems, with funding that goes through 2016. The Department of Health funds CSHS staff member Sue Burns' time on these grant activities.

In 2012, 98 percent of babies were screened for hearing loss, which is about 10,000 infants. 1,000 babies or 10 percent of the infants did not pass the hearing screening or required additional testing. Of those infants, 20 percent or 200 infants were lost to follow-up. EHDI programs strive to meet the goals of 1-3-6, which is to screen all infants by 1 month of age, complete evaluations by 3 months of age and have all children diagnosed with a hearing loss receive early intervention services by 6 months of age.

In 2010, 14 children who were diagnosed with congenital hearing loss were entered into the Oz eSP EHDI tracking system. According to national estimates, ND should be identifying approximately 30 infants a year. One reason for the discrepancy in numbers may be that not all infants identified with a hearing loss were reported in the tracking system.

ND EHDI is currently funded through federal grants, one of which received a 20 percent reduction this year. Dr. Carver asked if there are plans for state funds to be put into this program. Tammy commented that CSHS has attempted requests for state funds in the past but they haven't been included in the Governor's budget. Dr. Feldman asked if state funding is received, would federal funding be reduced. Sue commented that many states that receive state funding still receive federal funding. Most states use the federal funds for outreach, provider education and family supports.

Many hospitals have made hearing screening a standard of care, so the screening mandate may not be needed as much as a reporting mandate. Dr. Carver said that families should be educated about the importance of rescreening babies that are at high risk for hearing loss even though they passed their screening at birth.

Dr. Feldman motioned to request state funding for detection, follow-up care, and reporting. Dr. Carver seconded this motion. Motion carried.

CSHS Medical Eligibility

Gap areas in mental health: ADHD, Autism, and other mental health disorders

Because of a flat-funded budget, CSHS hasn't been able to add ADHD, autism or other mental health disorders such as depression, anxiety, conduct or mood disorders, etc. to its list of covered conditions.

This is a potential area to consider when requesting extra funds in the budget process. Dr Fiechtner stated that mental health diagnoses are hard to pin-point. It's not as "cut and dried" like other conditions, which makes it challenging to ask for more funding because you have to know what you are going to use that money for. CSHS staff are not getting as many calls for these conditions compared to a few years ago. Some families can't afford the medications for ADHD. Dr. Feldman doesn't think the cost of medication is as big of a problem, but the availability of generic or what is included on the formulary is an issue. She doesn't know if covering the cost of medications would be helpful. She thinks CSHS should look at intervention and access to mental health providers. There are two issues: 1) What should CSHS add to the list to pay for and how to best advocate for it, and 2) Where should CSHS direct its primary efforts? Survey data shows that there is a lot of need. The Department of Human Services does deal with mental health issues and may be able to get more funding. The Center for Rural Health is monitoring the number of specialists that are available in ND.

Dr. Fiechtner motioned not to add mental health conditions to the list right now since there is another department that deals with these issues but advised CSHS continue to advocate for mental health services and cover mental health conditions that arise as complications of CSHS eligible conditions. Courtney Koebele seconded this motion. Motion carried.

Financial Eligibility, Covered Services and Reimbursement Issues

Financial Eligibility

Melissa gave a brief overview of the children who have met the \$20,000/year payment limit. In the last five years, there have been only two children who reached the limit. One child had cancer and reached the limit in 2009. The other child had a cardiac condition and reached the limit in 2011. The first child did not have a primary source of insurance, leaving CSHS as the child's only source of coverage. The second child had an out-of-state surgery and hospitalization which caused him to reach the \$20,000 limit. Staff worked with the local CSHS county worker who encouraged the family to apply for Medicaid so they could possibly get retro-authorization for-out-of state care to avoid maxing out CSHS coverage, but the family did not follow through on the application.

Gap-filling Services

Continuous glucose monitors - CSHS is receiving requests for continuous blood glucose monitors and sensors from clients that are on Medicaid. Currently, Medicaid only covers continuous glucose monitors when the child is being considered for a pump, but not for long-term use. The child who it was being requested for already had a monitor when she was determined eligible for Medicaid, but they are not covering sensors for the monitor. CSHS has agreed to cover the sensors. Since this will be an on-going issue, CSHS may want to advocate for a change in Medicaid's policy.

Test strips - Medicaid allows 200 test strips in 30 days. CSHS typically follows Medicaid's limits with a few exceptions. Many children's physicians are requesting that they test more often, particularly when the child is involved with sports and physical education. CSHS has approved extra strips for these children with documentation of physician's orders. If these are therapeutic goals, CSHS needs to support the methods to achieve them. Medicaid changed its insulin pump policy to reflect the needs of the pediatric population. Medicaid often uses CMS guidelines which likely reflect the needs of the elderly populations rather than policies geared specifically for children. Dr. Connell hopes Dr. Betting can advocate for the insulin dependent diabetic child.

Treatment for infantile hemangioma - A child had a facial hemangioma near the eye with concerns that it would affect his vision. The dermatologist recommended treating it every two weeks with pulse dye laser treatment. CMS guidelines allow treatment once every 90 days so Medicaid typically follows this policy. CSHS staff have been working closely with Medicaid EPSDT staff to see if an exception

can be made due to medical necessity. CSHS advocates for changes in Medicaid policy if there are different guidelines for pediatric treatment. It's a unique case. Medicaid staff have been responsive to the needs of the child and are willing to look at the age appropriate guidelines and medical necessity.

Primary Care Reimbursement

At last year's meeting, the council approved the policy addressing coverage of care provided by a family practice physician, nurse practitioner, or physician's assistant when conducting a diagnostic evaluation relevant to a CSHS eligible condition and for Treatment Services related to pre and postoperative care, emergency care, short term management of an eligible condition and long term management when done in conjunction with a specialist. This has been going well.

Metabolic Formula

Tammy relayed that at this time only individuals with PKU and MSUD are able to receive formula through the CSHS metabolic food program. Children that have other metabolic disorders need to meet income guidelines of the CSHS Treatment program to receive assistance with formula. During the year, CSHS staff had worked with Medicaid partners regarding potential coverage of specialty formula for individuals with metabolic disorders. ND Medicaid decided not to cover metabolic food (formula) for individuals with inborn errors of metabolism since the legislature opted to not expand coverage for it during the last legislative session. Medicaid did add the coverage of nutritionally complete formula, for special metabolic needs, excluding inherited disease of metabolism. Examples of this type of formula include Glucerna, Pulmocare, Renalcal, etc. In order to be eligible, the individual must have a nasogastric or gastrostomy tube and the enteral nutrition formula must be the patient's sole source (90%+) of nutrition.

Issues with Orthodontic Care

CSHS sent a letter to Dr. Feil, the orthodontist on the CSHS Medical Advisory Council, with questions regarding orthodontic issues to get his input since he could not be at the meeting. The first question was should CSHS have a fixed payment for orthodontic services? Currently CSHS pays the claim at the full billed amount. The billed amount is broken down into monthly payments that extend through the expected length of treatment. Medicaid pays about \$3,500 for orthodontia and pays the full fee at time of banding. If a CSHS eligible child becomes eligible for Medicaid during orthodontic treatment, a formula is used to break out the banding fee and the number of months of treatment that have already been paid to determine how much of the Medicaid allowed amount will be paid. In the last year, Healthy Steps started covering orthodontia and pays \$4,500, which is also paid at the time of banding. If a CSHS eligible child becomes eligible for Healthy Steps, the child must meet Healthy Steps' point criteria (20 points) to be eligible for orthodontic services. Many children do not meet the required point criteria when they are mid-treatment. If the child does not meet the point criteria, CSHS has continued to provide the orthodontic care for the child. If the child does meet the point criteria then a formula that is similar to the one used by Medicaid is used to determine how much of the Healthy Steps fee will be paid. Both Medicaid and Healthy Steps require 20 points, while CSHS requires 25 points. Medicaid does not look to see if the child would still meet the point criteria if they are mid-treatment since they know that the child would have been eligible when the orthodontic treatment began. Healthy Steps may be changing the need to meet point criteria mid-treatment in the next year. If a child starts on CSHS and then becomes eligible for Medicaid then the cost gets transferred to Medicaid. The orthodontist may have been getting \$6,000 from CSHS but Medicaid pays \$3,500 and Healthy Steps pays \$4,500. Dr. Fiechtner feels there should be a standard fee. In Dr. Feil's letter, he stated that sometimes the children that score higher in points aren't always the highest cost and are easier to fix. Dr. Feil is working on a hybrid form that possibly all programs could use. Dr. Goldstein said that maybe CSHS should have a dental consultant to review these before approving. Most of the children we are covering don't have dental coverage. There is no standardized fee for orthodontics.

Dr. Martsolf stated that it may change the relationship with the cleft palate team. Dr. Fiechtner said that it's hard to have a fixed fee for cleft children. CSHS should leave it as is for cleft children, but maybe have a fee for handicapping malocclusion. It would be useful to work this through with other partners in the dental community. CSHS needs to explore this issue further with an ad hoc group.

CSHS had a child that ended orthodontic treatment seven months early. Should CSHS consider not paying the rest because treatment ended early? The braces were removed and a retainer placed due to bad hygiene and good position of the canines. Courtney Koebele stated she didn't think the orthodontist should be penalized for an early completion. Dr. Betting posed the question, are we paying for the result or the time?

Recommendations after the discussion include the following: 1) CSHS should explore having a standard fee with an ad hoc group, 2) There should be a consistent hybrid form for all programs, 3) Determine points needed to signify it's a CSHCN versus routine orthodontia based on functional impact, and 4) With mid-treatment, pay the provider for the result, not the time it takes.

Russell Silver Syndrome

The Legislature originally appropriated \$150,000 for the Russell Silver Syndrome program. This was cut to \$100,000 and now it's \$50,000 for the biennium. ND state law allows \$50,000 per child per biennium. Currently, there are four children enrolled in the Russell Silver Syndrome program. Two children are currently on Medicaid and one child has dual insurance. CSHS is currently only paying claims for one child. This could change when the two children on Medicaid age out of Early Intervention and may depend fully on CSHS for coverage. If so, having four children in the program could be very costly. CSHS is mostly covering formula right now and the annual travel expense for out-of-state expert care. The pharmacy hasn't been billing CSHS for growth hormone despite numerous enquiries regarding claims.

Programmatic Updates

Family Advisory Council

Tammy acknowledged Lori Hanson and Cheryl Klee as CSHS Family Advisory Council members and thanked them for their attendance. One of the main areas CSHS focused on this year was father involvement. Lori expressed her gratitude for being invited to join the meeting and for the council's willingness to listen and take their advice.

Project Carson

Project Carson is a family support initiative that provides support to families that have received a pre or postnatal diagnosis of special needs for their child. Advisory Council members were encouraged to make a referral to Project Carson if they are aware of a family that may benefit from this service. A brochure was included in the Medical Advisory Council packet. Project Carson parents will be presenting on this program at the next Title V staff meeting.

Clinics

New craniofacial clinic in Fargo - Sue shared that David Montes, DDS, an oral surgeon at Sanford, wants to start a new craniofacial clinic. His goal is to begin the clinic this summer. That would mean that both CSHS and Sanford would be offering a clinic in Fargo. Typically CSHS will host a clinic if there is a gap or need for the service. With Sanford offering a craniofacial clinic, is there still a gap in services for children with cleft lip and palate in the Fargo area? One difference between Sanford's clinic and the CSHS clinic is that Sanford would likely charge a fee and the CSHS clinic is free. Dr. Martsolf stated that some families can't afford a fee-based clinic. Dr. Martsolf said that discontinuing the CSHS cleft clinic could disrupt relationships with current team members and could also affect team

members' professional business too. It was recommended that CSHS wait and see how Sanford's clinic develops. It would be too soon to take away an established clinic that is free. The national trend is if it's available in the private sector then the public sector will likely reduce their services.

Select contracted clinics – The Diabetes Youth Outreach (DYO) Program holds six clinics a year in rural communities. CSHS funds this program, which also provides educational workshops and a family support group. The program has had extremely good documented results. There is \$73,369 in funding from CSHS for this program for the current biennium. The contract coordinator is retiring and a replacement has not been found. Should CSHS continue with the program? Is there a need for coordinated pediatric diabetes care in ND? The workshops and support groups are well-attended. There are smaller numbers of children at the clinics due to the rural population but the numbers have remained consistent. Dr. Martsof asked if it has improved because of the coordinator's work and will it get worse when she leaves. Dr. Connell worries about who the families will call if need arises. If they need to go to the Emergency Room, the drive can be long. Currently, the families have 24-hour access to a person because the coordinator gives families her personal cell phone number to call in the case of an emergency. Dr. Feldman asked if there are technology advances that can cover some of these bases. The consensus is that current care is not completely adequate and CSHS should continue to fund this program, if possible.

Autism diagnostic clinics – CSHS supports Great Plains Interdisciplinary Autism Diagnostic Clinics (GPIC) in Jamestown and Minot. The purpose of these clinics is to provide diagnostic services, including screening and follow-up services, to families of referred children. Referrals are usually made by local providers but can also be made by families. There are five clinics per biennium. Two children are screened at each clinic in an arena-style format. In this environment, the interdisciplinary team works in one room with the family present to perform screening evaluations and provide recommendations to the family.

Sanford Pediatric Developmental Evaluation Clinic (Fargo) – This clinic is for children age 6 months and up for whom a full developmental assessment is warranted. In the clinic, each child is evaluated fully by a speech therapist, occupational therapist, pediatrician and dietician. The families also are seen by a medical social worker and a registered nurse. The diagnosis of an autism spectrum disorder facilitates at least one follow-up visit with the child and family. These visits are intended to monitor the child's progress and ensure that appropriate services are in place for the child and family.

Altru Developmental Assessment Clinic - These clinics are sponsored by a grant through CSHS and provide annual developmental assessments for high-risk children in Belcourt and Fort Totten. A team of specialists perform comprehensive evaluations to determine the need for further services.

Altru's Pediatric Developmental Clinic - This clinic serves children who are considered to be at risk for developmental issues. Located in Altru's Main Clinic, the Pediatric Developmental Clinic integrates physical and occupational therapy screenings as well as nutrition services with the child's physician appointment. Together, the team then determines if the child has a need for additional services. Altru will be starting a Rehab Pediatric Therapies Screening Clinic with a focus on Autism screening. Funding is provided by a one-year \$30,000 grant through Medica, lasting from February 2012 through February 2013. They will see 8-10 children per clinic. The clinic dates are 4/4/2012, 6/6/2012, 9/5/2012, and 12/5/2012. There is the possibility for a 5th date yet to be scheduled. The clinic team will consist of a pediatrician, occupational therapist, physical therapist, social worker, and speech therapist. They will likely try implementing an "arena-style" approach. A follow-up letter will go out to the family after the clinic and the social worker will link the family to appropriate resources.

The Anne Carlsen Center is expanding their autism services. They will include one-on-one staffing in the home and community with a minimum of 25 hours of service per week for children and young adults. They provide information and referral resources for families. Diagnostic and evaluation services are based on individual need. They offer program coordination, planning, and development focused on specific goals and outcome as well as education and training for families and professionals. Most of these services are funded through the Medicaid Waivers, but the cost would not be prohibitive for families and they are willing to explore other funding options.

System of Care for Children with Special Health Care Needs

Autism

CSHS is revising the Resource Booklet for Children with Autism Spectrum Disorders with funding from the Support Autism North Dakota (SAND) grant. A concern is how to best address the topic of complementary and alternative therapies in the booklet. CSHS has tried to stay family focused, by giving a variety of options, since family support organizations are getting numerous inquiries regarding these complementary therapies. Working collaboratively with partners on the SAND advisory council, it was decided to add a bolder disclaimer to the complementary and alternative therapies section and list the therapies from most evidence-based to least evidence-based. However, some concerns from AAP Chapter members have been voiced. Some think that publications from the ND DoH should only include evidence-based therapies, such as those endorsed by the AAP. This is somewhat contradictory, as an article entitled “Management of Children with Autism Spectrum Disorders” dated October 29, 2007 in Pediatrics (the official journal of the American Academy of Pediatrics) stated that “It is important that health care professionals understand how to evaluate the evidence used to support all treatments, including CAM, psychopharmacologic, and other interventions.” Therefore, should these therapies be taken out of the booklet entirely, a disclaimer added listing evidence-based to least evidence-based, etc? Dr. Fiechtner stated that they shouldn’t be called alternative “treatments.” Dr. Goldstein stated that chiropractic care may help with children with sensory issues. Dr. Feldman suggested including them at the end with an indication that these are some therapies that others have found useful and a disclaimer to consult their physician. Lori stated that some parents may find them useful and some may not. Dr. Feldman said to include it and tell the families where to find the services. Providers should also know about these therapies so they can answer questions from families. Cheryl commented that each child is different and parents should have the opportunity to know what resources are available. Angela Richter asked if it should be broken down between established, emerging, and non-established therapies, rather than making it a focused area of the booklet. Dr. Connell commented that we need to be careful not to injure with some of these therapies if it’s not appropriate for the individual and know how to add it without hurting some but also helping others. Dr. Fiechtner said we should use scientific based therapy for the booklet. Dr. Betting suggested just putting in the National Standards website only as a good place to check on CAM. Dr. Feldman agreed with Dr. Betting. Tammy commented that it’s good middle ground. Consensus was reached to include content in the booklet on established, evidenced-based practices and include the website for the National Standards Report from the National Autism Center, which provides information about the efficacy of other interventions to help those who want to find out about emerging and alternative practices.

Support Autism in North Dakota (SAND) grant

Angela Richter, North Dakota Center for Persons with Disabilities, handed out a draft autism road map. It is a companion document to the resource booklet. She is looking for information to add or delete on the road map as they are trying to make it useful for any stage, when red flags appear, when the child is diagnosed, etc. It was suggested to combine “when to worry” and “who can help.” Dr. Betting asked if there should be answers after the questions. He also suggested moving “advocating” to the end of the road map. There are shortages of places to receive an autism evaluation. Staff at NDCPD are training autism diagnostic teams. It’s educationally based but they are trying to add a

medical component. Dr. Carver commented that the child needs to be diagnosed before they get the educational component. Dr. Connell suggested color coding the support resources to coincide with the colors on the roadmap. Financial help is in two different places, which may be confusing but it may be needed if families only need one area of the roadmap. It was recommended that state agencies and family support organizations be added to “advocating for services”. Consensus was given that this could be a useful resource.

Needs Assessment

According to the 2009/2010 National Survey of Children with Special Health Care Needs, ND has seen an increase of children with special health care needs from 12.2% to 13.9%. ND is improving in some areas of the survey and decreasing in others. The Medical Advisory Council packet included factsheets that provide information on ND’s ten state priorities for the Title V population.

Health Care Reform

Tammy encouraged Medical Advisory Council members to monitor the Insurance Department’s website for information regarding health care reform. The benefit plan has not been defined as of yet but if it’s similar to current plans, CSHS will likely have a need to continue gap filling. All were encouraged to be aware of what is happening with health care reform in ND and to advocate for the care they would like in place for children, especially those with special health needs. Courtney stated that many states are in the same position as ND with a federal-governing system.

CLOSING REMARKS/WRAP-UP

Six physicians have terms that will be expiring this year. They include Dr. Quisno, Dr. Kenien, Dr. Kemp, Dr. Martsolf, Dr. Carver, and Dr. Goldstein. Dr. Carver, Dr. Goldstein, and Dr. Martsolf have agreed to another term. Dr. Kemp said no to another term. Dr. Quisno and Dr. Kenien will be contacted to determine their interest.

Dr. Connell closed the meeting after giving a warm thank you to the committee for all their hard work and support.