

Children's Special Health Services
 Family Advisory Meeting
 February 8, 2014

Attendance:	
Family Advisory Council members	Cheryl Klee, Carla Peltier, Lisa Beckman, Moe Schroeder, Evelyn Klimpel, Joseph Liccini, Jennifer Restemayer, and Lori Hanson (phone).
CSHS Division staff	Tamara Gallup-Millner, Tina Feigitsch, Devaiah Muccatira, Carrie Tate, Melissa Evans, Kim Hruby, Tammie Johnson
Other	Kim Mertz and Gregg Reed from the Family Health Division
Welcome/Introductions/Announcements	<p>Tammy welcomed participants to the meeting and introductions were made.</p> <p>“What would you like your CSHS worker to ask about during a family interview that would make the interview process better” was asked as the meeting “icebreaker” with the following responses:</p> <ul style="list-style-type: none"> • Ask questions in a different way. • Ask how much families are paying out in bills. Families a lot of the time don't understand the financial aspect. • Ask how things are going. Sometimes families don't really know how to answer that. In a family's mind, everything may seem okay since they are used to their medical routine. • Ask about major events that happened over the last few months or how the year went. • Ask if anything has changed. • Break it down a little bit more. • If the family is able to meet or talk on the phone, then things may be going well at least that day. • Ask if school is ok (e.g., grades, peers, etc.) Focus on more day to day experiences. <p>The following announcements were made:</p> <p>A volunteer to be the Family Advisory Council representative at the Medical Advisory Council meeting on May 3, 2014 from 8:30-12:00 noon was requested.</p> <ul style="list-style-type: none"> • Moe, Cheryl and Jennifer indicated possible interest. <p>The following upcoming conferences or training opportunities were discussed:</p> <ul style="list-style-type: none"> • Family Voices of North Dakota is offering a Parent Leadership Institute on June 6-8, 2014. Families can also respond to a Family Survey at http://www.surveymonkey.com/s/PCLST97.

	<ul style="list-style-type: none"> • North Dakota Conference on Injury Prevention & Control – “Bringing the Pieces Together” October 1-2, 2014 at the Radisson Hotel in Bismarck, ND. • CSHS Care Coordination Training – September 9, 2014 at the Comfort Inn in Bismarck, ND. • 1st Annual North Dakota State Autism Conference - October 20-22, 2014 at the Ramada Bismarck Hotel (formerly Doublewood Inn) in Bismarck, ND. • Pathfinder Conference April 10-12, 2014 in Minot. Stipends may be available for parents who would like to attend.
Follow-up from November 2013 Meeting	<ul style="list-style-type: none"> • Updates were made to the membership list. • November 2013 minutes were accepted as written. • Tammy provided CSHS updates in response to the advice from the November 2013 meeting recorded on the Recommendation/Review form.
Affordable Care Act (ACA)	<p>CSHS staff provided an overview of CSHS and Navigator activities with the Affordable Care Act.</p> <ul style="list-style-type: none"> • Tammy recently completed a Maternal and Child Health Bureau Survey regarding payment for direct services. CSHS indicated spending about \$115,000 in federal funds per year for diagnostic and treatment services. Needs have not gone away with the Affordable Care Act so there is still a need for gap filling. • CSHS is linking families to Medicaid Expansion, North Dakota navigators that help with Marketplace enrollment, and making sure families are aware of the coverage and plans. • Care Coordination services have changed a little bit with the ACA . • Adjustments are also being made in CSHS informational resources for families (e.g., List of navigators now included in financial packet). • Handouts from the North Dakota Department of Human Services on Medicaid and Private Health Insurance for North Dakotans were shared. Council members indicated the information and options are difficult to understand. • Staff gave an update on Navigator activities based on a report from Donene Feist . It has been difficult for the navigators and some people are skeptical to enroll. For every five assisted, four qualified for Medicaid expansion and one qualified for the marketplace. Many scenarios are not cut and dried making the application process difficult. Family Voices has had an average of five calls a day specifically on the ACA. Nearly 4,000 have enrolled in the marketplace. Numbers for those enrolled in Medicaid expansion are not yet available. A definition of habilitative coverage is still lacking, which remains an issue for the CSHCN population. Some families may see a decrease in coverage for therapy visits in the marketplace because of this. Staff have learned that children can be on a waiver and enroll in the marketplace but their family is unable to receive a subsidy or tax credit. Outreach has been difficult (e.g., lack of educational materials and PSA’s, small community attendance at education/enrollment events, etc.). The group discussed that it could be difficult to understand

	<p>and navigate with multiple coverage sources within one family (e.g., mom has private insurance through work, dad is not covered under that plan so he could get coverage through the marketplace, and a child could be on Medicaid).</p> <ul style="list-style-type: none"> • CSHS has tossed around the idea of administrators becoming certified application counselors. Council members were receptive to the idea if staff time permits, especially if navigators are no longer available.
<p>Updates</p>	<p>The following are updates from the Department of Human Services.</p> <ul style="list-style-type: none"> • Medicaid (MA) Expansion - If a patient qualifies for MA expansion now, they will get a Sanford plan number. It makes it a little more difficult to check and document the correct coverage source at CSHS. The Sanford card indicates “Medicaid Expansion” on it. Council members wondered whether it looks like a Sanford plan when it pays out but CSHS staff wasn’t sure yet. • Department of Human Services Focus Group for House Bill 1378. DHS leadership is looking at ways to address kids with special health care needs more effectively. Options being considered include increasing the federal poverty level for the Buy in Program and adjusting the level of need criteria for the Medically Fragile waiver. The next meeting is scheduled for 2/19/14. • Members were encouraged to submit public comment for the Autism Waiver. The public comment period ends 2/13/14. • Efforts continue with the MMIS Project. This is the new system CSHS will use to pay claims. Melissa has been attending as many meetings as possible for training and testing. The new system may “go live” the second quarter of 2014, hopefully with limited impact to families. • An update was provided on childcare. There is a new DHS program called the Early Childhood Services Inclusion Support Grant Program, which is intended to increase the capacity of child care for children with special needs. Two Inclusion Specialists are also now available through Child Care Aware. Family income can now be higher to qualify for the Child Care Assistance Program. Highlights of discussion points follow below: <ul style="list-style-type: none"> ○ Childcare providers are possibly not applying for grants because facilities are full and they don’t have the capacity to care for more children. There are waiting lists. In some areas there is no daycare available at all or you have to try to reserve spots soon after finding out that you’re pregnant. ○ Facilities may not know that a child they care for has a disability or developmental delay, or think it would not apply to them. Training is needed. ○ Council members advised that these Informational sheets be included in childcare provider licensing packets and at other training opportunities through DHS and SAND. <p>National Update</p> <ul style="list-style-type: none"> • Tammy, Moe, Kim Mertz, and Devaiah commented on the Association of Maternal and Child

	<p>Health Program (AMCHP) conference that they attended in January 2014. Other families and state staff were encouraged to participate as it was a great learning and networking opportunity. There are pathways to family leadership within AMCHP.</p> <ul style="list-style-type: none"> • The group also discussed the MCH Transformation 3.0. At the federal level three major goals have been identified with the change. Tammy relayed many comments have been made about the lack of specific performance measures for children with special health care needs but reassured the group that the law requires this population be addressed. <p>The Department of Health update was postponed due to time constraints.</p>
Screening Updates	<p>Various screening updates were provided and discussed.</p> <ul style="list-style-type: none"> • Developmental/Autism Screening – The Supporting Autism in North Dakota (SAND) grant is addressing screening and early detection training for medical providers and childcare professionals. Discussion around this topic focused on getting information to childcare providers and the need to train childcare staff on how to talk to families about the red flags of autism. Outreach to rural communities was also suggested. • Newborn (Metabolic) Screening - A handout with updates on newborn screening fees and upcoming language revisions was shared. Council members were encouraged to share any feedback with Becky Bailey or Katie Bentz in the Family Health Division. • Hearing Screening –In ND, there is no state mandate for early hearing screening. EDHI staff at the ND Center for Persons with Disabilities submitted a new three year grant application. The program is looking for a pediatrician who will be an EHDI champion. • Critical Congenital Heart Disease (CCHD) – the Department of Health’ responsibility with CCHD is informational only. There is no mechanism in place to monitor how well screening is being conducted across the state but all agree that early identification is beneficial.
Children with Special Health-Care Needs Report	<p>Devaiah Muccatira, SSDI Coordinator and CSHS Research Analyst and Gregg Reed, MCH Epidemiologist in the Division of Family Health gave a presentation on Children with Special Health Care Needs based on data from the 2009-2010 National Survey of Children with Special Health Care Needs. The following comments were raised in response to the presentation:</p> <ul style="list-style-type: none"> • How can this information be used to further benefit families? • Children with chronic pain were likely part of a bigger picture. • The dollar amount of \$1,000 on medical expenses seems low. • Do families understand the questions they were asked when taking this survey (e.g., medical home)? • Some rural families have difficulty with travel costs and getting appointments with specialists. • Should the power point presentation be available on the website as it could be taken out of context?

	<ul style="list-style-type: none"> • There is a need to frame this data in a way that means something (e.g., depict 1 in 7 children as 1 red and 6 blue figures). • For professionals this would be helpful but for the average person this information may be overwhelming. • Add a summary slide at the end of the presentation.
<p>Family Advisory Council Project-Data Story Profile—Moe Schroeder</p>	<p>Moe relayed she has an idea for a project to get Family Advisory Council more actively involved. The data story profile is a way to pair personal stories with state data. It would give families a voice, could be therapeutic, and is a useful tool to show the connection between families and CSHS. Discussion highlights follow:</p> <ul style="list-style-type: none"> • Family stories are a way to connect with other families in the state and could be a means to communicate about services that may be available. • Stories can show successes, assistance available, gaps in services, and be a mechanism to reach out to others. • Family Advisory Council members could interview another CSHS family to help them with their story. • Council members advised that there is no need to compare personal stories to others. Some stories might not be quite as difficult as others, but someone out there may read a family story and connect with it. <p>The following council members agreed to help with the project: Moe, Jennifer, Cheryl and Joe were willing to help with family stories. Moe and Cheryl will design a template based on the legislative messaging project done by the Healthy North Dakota Early Childhood Alliance. The group will need to determine how best to use it when it's done (e.g., outreach packets, website, display booth, legislative session, etc.).</p>
<p>Reimbursement Forms/Adjourn</p>	<p>After members submitted reimbursement forms, the meeting was adjourned.</p> <p>The next Family Advisory Council meeting is scheduled for Saturday, May 3, 2014 from 1:30 to 4:30 p.m.</p>

CSHS Family Advisory Council Recommendation/Review Summary

Meeting Date	Advice	Action Taken
February 2014	<p>Incorporate suggestions to improve the family interview process.</p> <p>Solicit Family Advisory Council representation for the upcoming Medical Advisory Council meeting.</p> <p>Time permitting, CSHS staff should consider becoming certified application counselors to link families to the Marketplace.</p> <p>Recommend that informational childcare handouts be included in childcare licensing packets and disseminated through other DHS and SAND training opportunities.</p> <p>Suggest that SAND partners provide information about developmental/autism screening and train childcare staff on how to talk to families about the red flags of autism.</p> <p>Enhance CSHCN data presentations by “framing” data (e.g., depict one in seven by colored figures) and adding a summary slide at the end.</p> <p>Encourage more active involvement of CSHS Family Advisory Council members through a data story profile project. Moe, Jennifer, Cheryl and Joe volunteered to help.</p>	<p>Suggestions were included in new <i>CSHS County Connections</i> newsletter that was sent to county CSHS workers in March 26, 2014.</p> <p>Moe and Cheryl agreed to attend the Medical Advisory Council meeting on 5/3/14.</p> <p>No action has been to date as navigators are still available.</p> <p>CSHS staff e-mailed Jennifer Berry with the FAC recommendation. She relayed that although grant information has not been included in licensing packets, it has been disseminated to licensed childcare providers, licensers and Child Care Aware partners. A press release has also gone out. She recommended that parents of CSHCN also encourage their providers to look into the resources available to them. CSHS staff will address training recommendations at an upcoming SAND conference call on 5/8/14.</p> <p>CSHS staff followed up with SAND grant staff who relayed that at SAND trainings, childcare providers view a video from Autism Speaks on this topic: http://www.autismspeaks.org/whatisit/talking_to_parents_action_kit.php). Medical providers also see a video (module 3): http://www.cdc.gov/ncbddd/video/actearlycurriculum/). CSHS staff will address screening and training recommendations at an upcoming SAND conference call on 5/8/14.</p> <p>A summary slide was added to the end of the CSHCN data presentation before it was given to the CHS staff.</p> <p>Moe and Cheryl have drafted template materials for the council to review at the May 2014 meeting.</p>