

**Children's Special Health Services  
Family Advisory Meeting  
November 15, 2014**



Attendance:	
Family Advisory Council members	Carla Peltier, Lisa Beckman (phone), Joe Liccini, Sarah Carlson, and Lori Hanson (phone).
CSHS Division staff	Kim Hruby, Melissa Evans, Devaiah Muccatira, Tammie Johnson, Kodi Berg and Carrie Tate
Guest Speakers	Hilory Liccini, Teens Entering Adult Medicine (TEAM) Project Director and Rhonda Weathers, TEAM Project Coordinator
Welcome/Introductions/ Announcements	<p>Kim gave a warm welcome and announced that Tammy was unable to attend because she recently was married. Her new married name will be Tammy Lem. Other introductions were then made.</p> <p>Who's Leaving and who's new:</p> <ul style="list-style-type: none"> <li>• Donene stepped down from the Family Advisory Council; she is very busy with competing demands and felt like it was time to step down from the council.</li> <li>• Possible new member attended the meeting, Sarah Carlson. She has a young child with disabilities, is motivated to share the joy that her child gives, and to connect with other parents. She is part of the RICC (Regional Interagency Coordinating Council) in Region 8.</li> </ul> <p>Updates Regarding Council Membership Status:</p> <ul style="list-style-type: none"> <li>• Several members renewed their council slots.</li> <li>• There is now one vacant spot from Donene.</li> <li>• Sarah is attending this meeting as a trial run to see if she is interested in filling the vacancy.</li> </ul>
Follow-up from May 2014 Meeting	The May 2014 minutes were accepted as written, with Carla giving the initial movement to approve and Lisa seconding.
Federal & Departmental Updates	<p>Federal Update:</p> <ul style="list-style-type: none"> <li>• The first Notice of Grant Award (NGA) for the MCH Block Grant was received, which was a little bit lower than in the past.</li> <li>• The Family Ranking Sheet (FFY 2014 Ranking for the FFY 2015 Application) was reviewed. <ul style="list-style-type: none"> <li>○ This is a tool used to grade CSHS on family involvement in program administration. Scores were shared that compared how the council rated the division vs. how division staff rated themselves.</li> <li>○ Kim pointed out that the FAC actually gave the division a higher rating than staff had given themselves.</li> </ul> </li> </ul>

- A list of compiled recommendations for input into the FFY 2015 MCH Block Grant Plan Activities was shared. Top issues from the public input survey included:
  - access
  - mental health
  - awareness
  - insurance
  - care coordination
  - transportation
  - medical home
- Only collecting this feedback electronically may not be the best route of collection.

MCH transformation:

- The Block Grant guidance is going through a 2nd review right now, but has at least been released, so we know what we need to be working on.
- Measures have changed. The focus is more on maternal health than in years past.
- Measures were chosen in which we can “move the needle.” This means that we will be able to see improvement clearly through MCH programmatic efforts.
- CSHS focuses more on the child instead of mothers and the guidance seems to focus less on children with special health care needs than in the past.
- Kim Mertz and Tammy have submitted formal comments on the guidance in an effort to ensure that children with special health care needs are not forgotten.

Department of Health MCH Update :

- The Legislative Session is coming up this year and deadlines were distributed. Just a reminder that CSHS is able to provide information, as state agencies do not lobby.
- CSHS anticipates more legislation regarding autism and is looking at housekeeping changes to autism database. Kodi informed the council that all individuals diagnosed with autism spectrum disorder will be reported into the database. There will also be potential legislation to expand the autism waiver in DHS.
- CSHS suspects possible legislation regarding the Metabolic Food Program, specifically looking at other children with metabolic disorders that might require formula. Currently only individuals with PKU and MSUD receive formula at no cost. Children with other metabolic disorders have to qualify with income eligibility to be able to get formula through the CSHS Treatment Program.

- Tammie informed the group that the Metabolic Food Program has been seeing more expense with the influx of people on the program. For example, MSUD formula is almost double the cost of PKU formula. Typically, ND averages one new case per year, but CSHS has added three new clients in the last 4-6 months alone.

- Council member Carla inquired if ND is the only state that provides this. Kim and Tammie responded that they were unsure whether other states provide formula at no cost.

Collaborative Improvement and Innovation Network (CoIIN) update:

- This is an initiative aimed at reducing infant mortality. Staff attended a national CoIIN conference to jump start the initiative. North Dakota will focus on tribal outreach, engagement and intervention in the following areas:
  - Multi-system approach ensuring families engage in safe sleep practices, reduce commercial tobacco use and second hand smoke exposure, and increase rates of prenatal care, along with other risk factor-reducing efforts.
  - Improve family capacity to protect and promote their own health
  - Address impact of social determinants of health
  - A priority area identified as a collaborative initiative with SD for all population groups is to increase access to and quality of prenatal care and maternal care to decrease rates of early elective deliveries.
- ND started to work on CoIIN within the SSDI grant as well, and incorporated it into MCH Block grant activities. We will be starting with small tests of change to see how they go, and may use this as guidance for other projects if this quality improvement model works well.

ASD Database Update:

- CSHS has gone through the process of purchasing the database and should have it soon.
- The first ever, Autism conference was held in October, and over 300 people attended.
- An Expert Panel meeting occurred to get input on a variety of issues including what information should be reported and who is qualified to report.
- Kodi hopes that most of the suggested changes from the panel can be made, although some changes may require legislation.
- Many issues were brought up on the bill language and changes that may need to be made. There were concerns with DSM IV to DSM V transition, along with other issues with the wording in the law.
- Currently work is being done to develop new bill language and draft administrative rules. New Jersey is a great database role model for ND.
- After answering questions from the council, the following was also relayed:
  - Reporting will be mandatory for providers and confidentiality will remain a priority
  - This is not strictly for children as all individuals should be reported

	<ul style="list-style-type: none"> <li>○ Kodi will be evaluating how to update the database since diagnoses can change over time.</li> <li>○ The database will show where there is need for more services</li> </ul> <p>Status of Needs Assessment:</p> <ul style="list-style-type: none"> <li>● The state is required to do a Needs Assessment every 5 years. This will be conducted this year. Devaiah, Grace Najau, Kim Mertz and Tammy have been and will continue to work on this. Most of the initial survey information came from local public health and the state, other than from families. <ul style="list-style-type: none"> <li>○ CSHS needs more information from families. There will be another electronic survey. FAC members were encouraged to complete it and disseminate it to other families.</li> </ul> </li> </ul> <p>Budget:</p> <ul style="list-style-type: none"> <li>● The ND Department of Health Budget was submitted for the biennium. The Governor required an initial flat general fund budget.</li> <li>● ND Office of Management and Budget (OMB) checks the budget and then it goes to the governor and he makes decisions regarding the final Executive budget.</li> <li>● OARs , which are optional adjustment requests are also able to be submitted. <ul style="list-style-type: none"> <li>○ CSHS submitted an OAR for a medical home project. Tammie stated that the Medical Home Portal could be wonderful tool to assist families without a medical home. From the CSHS perspective, the portal could help with system development; however, others indicated the proposal appeared to be geared for clinicians so it was not recommended as a priority within the DoH. <ul style="list-style-type: none"> <li>▪ Clinics practicing medical home--Dr. Carver in Minot practices medical home along with his staff. Sanford Fargo is also working on medical home and has been certified through Minnesota.</li> </ul> </li> </ul> </li> </ul>
CSHS Work Activities	<ul style="list-style-type: none"> <li>● The annual County Training event was held in September. CSHS works through the county social service offices in ND instead of public health, and holds training every 1-2 years to keep local staff abreast of changes.</li> <li>● The CSHS Policy, Procedure, and Resource Manual were updated this year, and manuals were disseminated at the County Training event. <ul style="list-style-type: none"> <li>○ Any council member who would like a manual is more than welcome to have one. CSHS usually updates the manual every 5 years.</li> </ul> </li> <li>● Site visits were completed at the following: <ul style="list-style-type: none"> <li>○ Williston GPIC autism clinic</li> <li>○ Cardiac clinics in Fargo, including both Sanford and Essentia</li> <li>○ Belcourt's Developmental Disorders clinic through Altru.</li> </ul> </li> </ul>

- CSHS staff conduct site visits to provide technical assistance and recommendations for quality improvement. Staff target programmatic areas that are experiencing challenges. Some services are excellent while others are lacking on follow up and coordination with families.
- A council member was interested in attending a Cerebral Palsy clinic in Fargo for her own child, but it is a long trip.
- Staff relayed that there has been no news of multidisciplinary clinics expanding to other areas of the state at this time.
- CSHS does accept applications for funding every 2 years, including those interested in supporting multidisciplinary clinics throughout the state. Anyone is welcome to apply for that funding.
  - CSHS administrative staff independently review each application and score them. Applications with the top cumulative scores receive funding, based on budget availability.
  - CSHS is interested in funding services throughout the state, and would encourage proposals from the western side of the state with all the growth there.
- Follow-up newborn screenings from Iowa are going well. Tammie follows up with the families that are undergoing testing for a potential diagnosis.
  - Physicians get notification at the same time as CSHS, so Tammie waits for a few days before contact is made to the family. CSHS has received an increase on diagnoses of hemoglobin traits with the increase in population that has been moving into the state. FAC members were asked if it was beneficial for CSHS to continue to make a phone call to families, or would sending a letter to families be better?
    - Council members suggested:
      - Whichever the response, it should be consistent with a phone call or a letter.
      - Would prefer a phone call, so that they can ask questions.
- With some of the traits that are diagnosed, the physician has not contacted the family and the call can catch the family off guard. Do we keep doing the phone call or send these with traits a letter ?
  - Council members suggested:
    - Maybe contact the physician first to see if they contacted the family. If they have then you know if the family knows, and then you can follow up with the family.
    - Evaluate the protocol that the physicians use, then you may know when to contact the families.
- CSHS Family Handbook goes out yearly to families with annual reviews. The handbook goes through some of the guidelines of our program and breaks it down. Does CSHS need to continually issue this out yearly, or if families get it once, is that enough? CSHS does send out a packet yearly, and that could include a note with the link to our website where the handbook is available.
  - Council members suggested:
    - Maybe every 3 years, instead of every year, or every 5 years.

	<ul style="list-style-type: none"> <li>▪ If a family has received a revised one, then send out a link each year in the packet of information.</li> <li>▪ Send out a simpler version, or since nothing changes just provide a link to the website.</li> <li>▪ Make it available at the counties, where they could pick it up if they would like a copy.</li> </ul>
<p>TEAM – Teens Entering Adult Medicine</p>	<p>Guest Speaker: Hilory Liccini, Project Director and Rhonda Weathers Project Coordinator from the North Dakota Center for Persons with Disabilities. TEAM (Teens Entering Adult Medicine) is a grant funded project for one year with the potential of a second year. The goal is to develop and implement or aid parents, physicians, and teens/youth.</p> <ul style="list-style-type: none"> <li>• Currently in the Williston, Jamestown, and Minot areas. The projects targets youth with special health care needs and is designed to train and equip them with the health care transition through web-based training.</li> <li>• Focuses on the Gottransition.org – six core elements</li> <li>• MSU will be using their technology “Go animate program” – that will be used to design each webisode.</li> <li>• Webisodes will be 5-7 minutes long, so that it can get information to a youth without too much information overload.</li> <li>• An example of a goal would be to help assist them schedule their first appointment. Typical 18 year olds will not know their comprehensive medical history, so this is a struggle for an 18 year old with developmental delay or special health care need. They may even consider utilizing a young adult with developmental delay as a consultant.</li> <li>• Currently NDCPD is piloting with pediatricians in Williston, Jamestown, and Minot. Eventually staff would like it available to all youth across the state.</li> <li>• NDCPD would like feedback or tips on what to put in the modules. What would be useful or what would have been useful to have?             <ul style="list-style-type: none"> <li>○ Council members suggested:                 <ul style="list-style-type: none"> <li>▪ Will this be free to families?</li> <li>▪ Cultural differences? Or economic factors? Would there be solutions or options to these factors.</li> <li>▪ Self-advocacy efforts should be focused on as well.</li> <li>▪ Is there an opportunity for them to network with each other? May have to have releases to have that available, possibly incorporate that in somehow.</li> <li>▪ Navigating health insurance. Getndcovered.org maybe a tool to reference ND specific information. Use lay-terms that families can understand.</li> <li>▪ Some clinics may not make an appointment for the youth. Clinics may need to work/train on this as well.</li> <li>▪ Health insurance – many things can be available to these individuals and they may have multiple coverages. What role does the specialist play, as well?</li> <li>▪ Youth need to know the process of making an appointment; you need to know who you need to see, why, routine visit or illness? Specific information may be needed.</li> </ul> </li> </ul> </li> </ul>

	<ul style="list-style-type: none"> <li>▪ Where you live also has an impact on who you see, when you can see them, and if the providers accept the coverage you have.</li> <li>▪ Have a place for the information that the youth has (e.g., cell phone) and keep certain information for the next time they make an appointment.</li> </ul> <ul style="list-style-type: none"> <li>• Tammie offered to share the transition presentation she had put together; Hilory was interested in receiving that.</li> <li>• Hilory plans to start with the first couple modules around February. The goal is to have 15 enrolled, 5 enrolled with each pediatrician in the pilot program. Then they can look at expanding this throughout the state.</li> <li>• Rhonda, project director for the ND Medical Home project dispersed the Fundamental of Medical Home brochure. The Course is still available online and is self-paced.       <ul style="list-style-type: none"> <li>○ Council members suggested:           <ul style="list-style-type: none"> <li>▪ Maybe this could be set up as a Family Voices (FV) topical call. Rhonda replied that FV does have a Medical Home topical call, and this would be good to discuss on there.</li> </ul> </li> </ul> </li> </ul>
<p>Reimbursement Forms/Adjourn</p>	<p>The Family Advisory Council's Messaging Project was not discussed and will be followed up on at a later time, due to Moe being unable to attend the meeting.</p> <p>After members submitted reimbursement forms, the meeting was adjourned.</p> <p>The next Family Advisory Council meeting is scheduled for Saturday, February 21, 2015 from 9:00 a.m. to 12:00 p.m.</p>

**CSHS Family Advisory Council Recommendation/Review Summary**

Meeting Date	Advice	Action Taken
November 2014	<ol style="list-style-type: none"> <li>1. Appoint Sarah Carlson to the CSHS Family Advisory Council.</li> <li>2. Consider alternatives to family engagement/public input in addition to electronic surveys.</li> <li>3. Continue to use a phone call for Newborn Screening follow-up, since families can ask questions. Evaluate protocols or check with physician first to ensure the family has been notified of a potential positive result.</li> <li>4. Consider sending out hard-copies of the Family Handbook every 3-5 years, or just send a link to the Family Handbook on the CSHS website. Also make sure it's available at county social service offices.</li> <li>5. Send FAC recommendations for the TEAM project and the ND Medical Home project to NDCPD staff.</li> <li>6. Send CSHS transition presentation to NDCPD staff working with the TEAM project.</li> </ol>	<p>Appointment was made by Dr. Dwelle, NDDoH State Health Officer.</p> <p>A qualtrics electronic survey is planned winter/spring 2015. Staff brainstormed additional ideas to better engage families including: updates at FAC meetings, Family Voices topical call, and presentation at Pathfinder conference.</p> <p>Tammie has continued with phone calls, and has been waiting approximately 2 weeks before calling. This has helped give physicians time to visit with families.</p> <p>Since the Family Handbook was revised, all families have now received the updated publication. Staff will consider sending families a hard-copy every 3-5 years with an electronic link every review period.</p> <p>Minutes with FAC recommendations were sent to Hilory and Rhonda at NDCPD.</p> <p>Tammie sent the transition presentation she had developed to Hilory in November 2014.</p>