

**Children’s Special Health Services  
Family Advisory Meeting  
May 2, 2015**



Attendance:	
Family Advisory Council members	Joe Liccini, Cheryl Klee, Moe Schroeder, Sarah Carlson, Clifford Klimpel (in place of Evelyn), and Lisa Beckman.
CSHS Division staff	Tamara Lelm, Dr. Joan Connell, Kim Hruby, Devaiah Muccatira, Tammie Johnson, Kodi Pinks, Tina Feigitsch and Carrie Tate
Welcome/Introductions/ Announcements	<p>Tammy gave a warm welcome and everyone introduced themselves and provided brief family updates.</p> <p>The following announcements were made:</p> <ul style="list-style-type: none"> <li>• CSHS staff changes - Tina Feigitsch was promoted to Melissa Evan’s position as Claims and Eligibility Administrator.</li> <li>• Upcoming conferences/training opportunities were announced: <ul style="list-style-type: none"> <li>➤ Dakota Conference on Rural and Public Health, June 2-4, 2015 in Minot</li> <li>➤ Family Voices Empowering Parent Leaders as Advocates Project, June 5-7, 2015 in Edgeley</li> <li>➤ ND Federation of Families for Children’s Mental Health Youth Transition Conference, July 19-20, 2015 in Bismarck</li> <li>➤ ND Autism Spectrum Disorder Conference, Oct 21-23, 2015 in Fargo</li> </ul> </li> </ul>
Follow-up from February 2015 Meeting	<p>Tammy reviewed the recommendations from the Family Advisory Council’s February meeting.</p> <p>When discussing ways to better inform families about changes with the MCH block grant, Moe suggested that Tammy provide a Title V overview at a follow-up conference call for attendees of the Family Voices Leadership Institute. Information could also be shared on CSHS services and opportunities for family involvement.</p> <p>When discussing the family messaging project that the Family Advisory Council worked on, members suggested that CSHS consider sharing it as a best practice in AMCHP’s Innovation Station. Other states could learn about the process and tools used to solicit family stories and implement a similar project with their respective Family Advisory Councils.</p> <p>The February 2015 minutes were accepted as written after a minor correction was made in the recommendation summary. It was noted that both Devaiah and Kodi presented at the Pathfinder Conference in April 2015.</p>
2015 Medical Advisory Council Meeting	2014 Medical Advisory Council meeting minutes were distributed.

Dr. Connell, CSHS Medical Director, summarized highlights of the 2015 Medical Advisory Council meeting. Family Advisory Council members, Moe, Sarah, and Clifford (in the place of Evelyn) attended the meeting. Highlights follow:

- Multidisciplinary clinics – A recommendation was made for CSHS to engage health systems to encourage providers to participate in CSHS supported cleft clinics. Providers receive an honorarium when they participate. Although this a fraction of what providers usually receive, it's not the only deciding factor in participation. A bigger issue is the time it takes away from current patients. Increasing volume without compromising care to improve efficiency was also recommended.
- Naturopaths – The council discussed whether CSHS should approve naturopaths as providers. A bill regarding naturopaths failed in the last legislative session. Currently they can't do the type of things we reimburse so it was advised that CSHS not add them to the specialist provider list.
- CSHS medical eligibility – Some conditions on the CSHS list were broadened to open up the field of coverage. Auditory processing disorder is difficult to diagnose and may require behavior therapy. It was not added to the eligible condition list as the council determined the issue needed further study.
- Diagnostic policy – No firm decision was made regarding diagnostic reevaluation and treatment services. There is overlap between the two.

Sarah commented that providers had excellent participation and showed a willingness to help, which was very encouraging to a parent. Moe added that you could see the struggle the providers have and how they are overwhelmed as well. Clifford commented that the providers seemed very dedicated to children, had good discussions, and seemed to enjoy their time together.

Council members asked how CSHS determines what conditions are covered. Dr. Connell referred to the CSHS list of eligible conditions and relayed that CSHS can make additions based on several criteria, but it has to be addressed within the division's approved budget. Some recommendations have come up because of a specific patient or parent request. Tammy added that historically in 1935 they served "crippled children", mainly children with orthopedic issues. CSHS has a history of serving children with birth defects/congenital anomalies. The more recent trend for children with special health care needs focuses on children with complex needs.

Sarah asked if a study could be done to see how CSHS-supported multidisciplinary clinics are improving things for families, as there was a lot of discussion about clinic participation during the Medical Advisory Council meeting. As a parent, seeing a provider at a clinic that shows dedication to their child can be a great motivator to switch to that provider. Dr. Connell referred to studies attempted with the asthma clinics. They may only show short term benefits when long term benefits

	<p>could also be important. Staff added that without the buy in with the institutions, the providers are not always able to participate in clinics. It is good to have those dedicated providers at the clinics that help with recruitment of other providers. Other things to consider include:</p> <ul style="list-style-type: none"> <li>• Provide a potential provider data that “proves” clinic participation provides revenue for physicians that participate.</li> <li>• Recruit a physician who will be a champion for the clinics.</li> <li>• Utilize retired physicians.</li> <li>• Try and address physician burn-out.</li> </ul>
MCH Block Grant Application	<p>Tammy relayed the MCH Block Grant application will be submitted in July 2015. The following items were discussed:</p> <ul style="list-style-type: none"> <li>• Recent MCH survey results (part of five-year needs assessment): 222 people responded to the survey, 4% of which identified themselves as a family member. Tammy relayed that 222 responses was an improvement compared to previous years. 184 out of 222 agreed on the 10 priorities that were chosen. For those that didn't agree, developmental screening was the most frequent area mentioned as an alternative. Tammy indicated that other partners are addressing the issue (e.g., Prevent Child Abuse ND, Child Care Aware, etc.). A handout was provided with details regarding all of the survey responses.</li> <li>• Ideas for family/consumer partnership: Tammy relayed that in the new grant guidance, a narrative description is required regarding family/consumer partnership rather than the ranking form that was submitted in previous years. Use of a family consultant could support this effort; however collective ideas from the whole council were also determined helpful.</li> <li>• Possible strategies (general approach to address state priority needs) that should be included in the five-year state action plan table for FFY 2016: A draft action plan on transition was shared so council members could see what was expected when the grant is submitted in July.</li> <li>• Family Advisory Council volunteers to possibly review the block grant application prior to submission and/or attend the federal MCH Block Grant review August 24, 2015 from 8-5 in Bismarck include: Moe, Sarah, and Lisa.</li> </ul>
Administrative Items	<p>Family Advisory Council member participation – Assessment results and possible Quality Improvement (QI) project: Kim shared results of an audit which addressed Family Advisory Council attendance at 12 meetings held from 2011-2014. According to Family Advisory Council bylaws, 2-4 meetings per year must be held. The total average attendance for 2011-2014 was 64%. The goal of 75% is a physical attendance goal; the current 64% average does not include members who participate by phone. CSHS would like to increase attendance to 75% and address this as a QI project to assure effective family engagement and active partnership. Council members relayed 70% was a more realistic goal.</p> <p>Discussion followed on what CSHS or Family Advisory Council membership could do to increase attendance:</p> <ul style="list-style-type: none"> <li>• Improve meetings – use technology (video or teleconference meeting), increase activity of members, inform</li> </ul>

members about available services at meetings, rotate meeting locations, have a picnic meeting with food and outdoor activities

- Change membership requirements – limit terms, reduce number of meetings per year
- Increase member commitment to physical attendance

The group thought that the average number of meetings held per year (3) is a manageable number and that “good attendance” is defined as more family members than staff in attendance. A question was asked if families could delegate a proxy if they were not able to attend. Tammy responded that participants that aren’t appointed can’t be paid which might be problematic. Another suggestion was that if a council member was unable to attend a meeting they could volunteer to help in other ways within their community (e.g., handing out CSHS brochures to providers to increase outreach, attending clinics, talking with families or other professional staff, working on the Block grant, etc.).

The group reviewed a list of ways families could be engaged:

- Advisory Committees
- Strategic and Program Planning
- Quality Improvement
- Workforce Development
- Block Grant Development and Review
- Materials Development
- Advocacy

The Family Advisory Council bylaws were distributed and reviewed. Council members agreed that no changes were needed.

Tammy reviewed membership terms that end after the May 2015 meeting. Three terms are up: Carla, Evelyn, and Jennifer. They will be contacted regarding continued interest in the council. Laura resigned as she has not been able to attend very often due to competing priorities with her family. Suggestions for a council member that would be Laura’s replacement included a young adult, family representatives that have utilized CSHS services and come from more rural areas, or another dad to bring more of the male perspective to meetings.

<p>CSHS Program Updates</p>	<p>Review new educational materials - Stella's story, cost share fact sheet and ASD database brochures:</p> <ul style="list-style-type: none"> <li>• Feedback has been excellent on Stella's story, which is on the CSHS website, included in cleft gift boxes, and distributed at cleft clinics. It is a good way to show families they are not alone. Families at the last cleft clinic and many of the providers took a copy and many comments were given on how much they loved it. Moe stated that Early Intervention families were not told about CSHS. Additional family stories that highlight CSHS program involvement would be a nice way to highlight services that CSHS has available. Council members indicated that families don't realize that CSHS is often funding services they receive.</li> <li>• Cost share fact sheet – Melissa put together a draft fact sheet. Kim discussed what cost share is and how it is available to families that may be over established income eligibility levels. Discussion revolved around the following: Do county workers know about cost share? Kim responded that they should, but CSHS staff will inform the county staff about this new fact sheet at an upcoming polycom refresher training to be held May 21, 2015. Council members requested information about the training also be sent to them. Suggestions for the fact sheet included the following: <ul style="list-style-type: none"> <li>➤ Bold the second sentence after the first bullet – All medical expenses for any other family members incurred in the same month can reduce the cost share.</li> <li>➤ Some examples might be helpful on the back of the sheet; keep the front of the sheet simple.</li> <li>➤ Reference the 90 day retro rule on the fact sheet</li> </ul> </li> <li>• The ASD database brochures were reviewed. The provider brochures are technical and discuss the reporting requirements for reporters. The family brochures give an overview about the ASD database and its purpose. Feedback about the drafted brochures was received from expert panel members, Family Voices staff, and Pathfinder staff. Advice was sought on how and where to disperse these brochures. Recommendations included: <ul style="list-style-type: none"> <li>➤ Send the brochures in the clinic directory mailing and insert them inside of the Autism Resource Booklets.</li> <li>➤ Provide a supply to family organizations, advisory groups, ASD clinics, key providers that diagnose and treat children with ASD, professional meetings, (e.g., NDMA, family practice, ND AAP, etc.).</li> </ul> <p>It was noted that approval from corporate health care systems may be needed in order to have the brochures available at all Sanford locations. Any further advice or recommendations can be sent to Kodi.</p> </li> </ul>
<p>Reimbursement Forms/Adjourn</p>	<p>After members submitted reimbursement forms, the meeting was adjourned.</p> <p>The Family Advisory Council meeting that was scheduled in August was cancelled due to projected low attendance. The next Family Advisory Council meeting is scheduled for Saturday, November 14, 2015 from 9:00 a.m. to 12:00 p.m.</p>

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

Meeting Date	Advice	Action Taken
5/2/2015	<ul style="list-style-type: none"> <li>• CSHS provide a Title V overview and CSHS-related information for Family Voices Leadership Institute attendees</li> <li>• Share family messaging project with AMCHP Innovation Station</li> <li>• Ideas to increase provider participation at clinics               <ul style="list-style-type: none"> <li>○ Provide data that clinic participation provides revenue</li> <li>○ Recruit a physician “champion”</li> <li>○ Utilize retired physicians</li> <li>○ Address physician burn-out</li> </ul> </li> <li>• Consider use of a family consultant in addition to council input for the family/consumer narrative in the MCH Block Grant application</li> <li>• Contact possible volunteers to review the MCH Block Grant or attend the review to be held 8/24/15 in Bismarck (Moe, Sarah, and Lisa)</li> <li>• Consider suggestions to increase member participation in advisory council meetings               <ul style="list-style-type: none"> <li>○ Improve meeting</li> <li>○ Change membership requirements</li> <li>○ Increase member commitment to physical attendance</li> <li>○ Consider alternative options for “participation” by council members</li> </ul> </li> </ul>	<p>Tammy presented an overview for Leadership Institute attendees on 9/21/15.</p> <p>No activity to date.</p> <p>Staff have recruited a retired physician to help with an upcoming Bismarck Cleft clinic.</p> <p>No activity to date.</p> <p>Potential volunteers were contacted. Donene Feist and Moe Schroeder attended.</p> <p>No activity to date.</p>

	<ul style="list-style-type: none"> <li>• Recruit new Family Council members for vacant positions on the council based on the following criteria: <ul style="list-style-type: none"> <li>○ Young adult</li> <li>○ Family representatives utilizing CSHS services, perhaps from a rural area</li> <li>○ Male</li> </ul> </li> <li>• Solicit addition family stories that highlight other CSHS programs</li> <li>• Send information about the May 21, 2015 polycom training for CSHS county social staff to council members</li> <li>• Consider the following changes in the Cost Share fact sheet: <ul style="list-style-type: none"> <li>○ Bold second sentence after 1<sup>st</sup> bullet</li> <li>○ Add examples on back of sheet</li> <li>○ Reference the 90 day retro rule on the fact sheet</li> </ul> </li> <li>• Consider recommendations for distribution of the ASD database brochures: <ul style="list-style-type: none"> <li>○ Add to clinic directory mailing</li> <li>○ Include them in ASD resource booklets</li> <li>○ Provide supplies to family organization, advisory groups, ASD clinic, key providers, disperse at professional meetings, etc.</li> </ul> </li> </ul>	<p>Reappointed or recruited new council members that met suggested criteria.</p> <p>No activity to date.</p> <p>Council members were e-mailed information. Jen attended on behalf of the council.</p> <p>The fact sheet was revised by bolding recommended sentence. This resource was used at the May 2015 polycom training for county staff.</p> <p>Brochures have been added to ASD resource booklets and supplied to various groups and organizations for dissemination. Plans are to include them with the clinic directory mailing in December/January.</p>
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