

**Special Health Services (SHS)  
Family Advisory Council Meeting  
September 15, 2018**

Attendance:	
Family Advisory Council Members	Joseph Liccini, Marie Vetter, Garrett Schultz, Moe Schroeder, Abbi Berg, Evelyn Klimpel, Clifford Klimpel
SHS Division Staff	Tamara Lelm, Kim Hruby, Tammie Johnson, Amy Burke, Joyal Meyer, Jaime Conmy, DeNae Tokach and Peggy Masset
Welcome and Introductions	<p>Jaime Conmy and Kim Hruby facilitated the September 15, 2018 meeting along with Joseph Liccini and Moe Schroeder (Family Voices staff).</p> <p>Tamara Lelm provided the welcome:</p> <ul style="list-style-type: none"> <li>• Marie Vetter and Abbie Berg, new members of the council, were introduced.</li> <li>• Also introduced was Krissie Guerard, the DoH Health Equity/MCH Partnership Coordinator, attending as a guest.</li> <li>• The focus for this meeting is to orientate the council to Title V.</li> </ul>
Icebreaker	<p>Icebreaker activity – Would you Rather?</p> <ul style="list-style-type: none"> <li>• A list of random questions was asked of those in attendance, and a clicker system was used to gather responses on the different topics.</li> <li>• An example of a question is: What other options would you like for attending the FAC meetings? <ul style="list-style-type: none"> <li>A. In Person</li> <li>B. Polycom</li> <li>C. Over a web meeting (e.g., Zoom, go to meeting, WebEx)</li> </ul> </li> </ul> <p>All in attendance would like to meet in person</p>
Announcements	<p><u>Upcoming Conferences/Training Opportunities:</u></p> <ul style="list-style-type: none"> <li>• SHS Biannual County Training Event – October 23 in Bismarck</li> <li>• ND Autism Conference – October 24-25 in Grand Forks</li> <li>• Association of Maternal &amp; Child Health Program (AMCHP) – March 9-12 in San Antonio, TX</li> <li>• North Dakota Disabilities Advocacy Consortium (NDDAC) – November 7-9 in Bismarck</li> </ul> <p><u>Additional Trainings and Connections – Compiled by Family Voices of ND Staff</u></p> <ul style="list-style-type: none"> <li>• Additional opportunities for families to get involved were shared, and council members were encouraged to take advantage of various topics of interest.</li> </ul>

	<p><u>Newborn Screening (NBS)</u></p> <ul style="list-style-type: none"> <li>• Tammy Lelm publicly acknowledged Garrett for sharing his moving family story at the NBS Conference in July and doing such a wonderful job.</li> <li>• State staff asked family members if they would share feedback regarding the newly developed survey regarding long-term follow up. <ul style="list-style-type: none"> <li>○ The council agreed they would be willing to do this for the Newborn Screening Program.</li> </ul> </li> </ul>
<p>Follow-up from the May 5, 2018 Meeting and Approval of Minutes</p>	<ul style="list-style-type: none"> <li>• Minutes were accepted as written and the Recommendation/Review Summary from the May 5, 2018 meeting was reviewed and discussed.</li> </ul> <p><u>Special Health Services Division Family Advisory Council Guidelines</u></p> <ul style="list-style-type: none"> <li>• The name was officially changed from bylaws to guidelines.</li> <li>• Major changes were addressed, including: <ul style="list-style-type: none"> <li>○ Length of Membership—There will be no restriction on years of membership.</li> <li>○ Term end – The parent’s term will end when their child turns 21 years of age. If a young adult is representing themselves, the membership will end at age 26.</li> <li>○ Attendance – A member that misses two consecutive meetings will be contacted by a SHS staff member to discuss their attendance. A member that misses three consecutive meetings, without any communication to SHS, will be thanked for their service and notified that due to the lapse in attendance, SHS will recruit a new member in their place.</li> </ul> </li> </ul>
<p>Maternal and Child Health (MCH) and the History of Title V</p>	<p><u>History of Title V</u></p> <p>A slideshow regarding the history of Title V within Maternal and Child Health (MCH) from 1909 to present was shared, including the history of Special Health Services.</p>
<p>Orientation to the SHS Division</p>	<p><u>Federal and State Mandates</u></p> <ul style="list-style-type: none"> <li>• Handouts were used to educate the council regarding current mandates, including some that are new to the SHS Division due to the DoH realignment last year, including: <ul style="list-style-type: none"> <li>○ Newborn Screening – metabolic and genetic disease screening tests</li> <li>○ Testing and Treatment of Newborns</li> </ul> </li> </ul> <p><u>Division of Special Health Services Programs and Services</u></p> <ul style="list-style-type: none"> <li>• The new Division Overview Fact Sheet was shared with the council and used as a tool to orientate new council members.</li> </ul> <p><u>Newborn Screening Long Term Follow-up</u></p> <ul style="list-style-type: none"> <li>• Long term follow - up identified through screening process to best serve the population at large</li> </ul>

- Questions asked to the Family Advisory Council were the following:
  - How long should we follow up?
  - What kind of follow up would you like to see?
  - Who should we send follow up survey to?
  - What should the role of the follow up be?

Title V MCH Block Grant—Overview Provided by Tammy Lelm

- The MCH Block Grant includes all of Title V.
  - There is a split of 57% federal funds, 43% state funds.
- The allocation for each year for the MCH Block Grant is as follows:
  - 2017 \$1,733,640 (actual federal funding), state match of \$1,318,364
  - 2018 \$1,733,640 budgeted federally, with a notice of award on 7/19/18 of \$1,739,627 federal funding. Currently unsure of the final state match, but \$1,300,231 was budgeted.
  - 2019 \$1,725,639 budgeted federally, state match \$1,294,379 was budgeted.
- 30% of MCH Block Grant dollars are required for Children with Special Health Care Needs (CSHCN) (protects funding for this population).
- The Maintenance of Effort (state match) is required at a minimum of \$1,206,293 (cannot go under this).

Take-Away Points from the Block Grant Overview:

- Federal Dollars - \$1.7 million
- State Dollars – \$1.3 million
- Flat funding from federal grant

Biennial State Budget (2 year) 2017-2019—Overview Provided by Tammy Lelm:

- Now includes Newborn Screening
- Salary line \$1,492,582 (39%)
- Operating line \$763,313 (20%)
- Grants line \$1,591,098 (41%)
- Total \$3,846,993
- General \$1,917,342
- Federal \$1,900,914
- Other \$28,737

A budget gives you authority to spend. However, Expenditures are limited to the actual funding received.

- We budget 2 ½ times the MCH Block Grant/state match, since there are 2 years allowed to spend one year of federal funds allocated.

	<p><u>Federal Fiscal Year Expenditures – CSHCN in MCH Block Grant 2017 (10/1/16 – 9/30/17):</u></p> <ul style="list-style-type: none"> <li>• Payroll \$569,969.38</li> <li>• Grants (counties) \$126,824.98</li> <li>• Contracts \$127,798.45</li> <li>• Data Processing \$10,979.39</li> <li>• Metabolic Food \$80,055.78</li> <li>• MMIS Claims \$196,570.50</li> <li>• Indirect \$60,585.50</li> <li>• Remaining expenses \$70,111.43</li> <li>• Total \$1,242,895.41             <ul style="list-style-type: none"> <li>○ General \$764,793.04</li> <li>○ Federal \$423,567.72</li> <li>○ Local \$54,535.00</li> </ul> </li> </ul> <p><u>Take Away Points:</u></p> <ul style="list-style-type: none"> <li>• Direct \$276,627 (22%)             <ul style="list-style-type: none"> <li>○ Claims, medical food</li> </ul> </li> <li>• Enabling \$238,174 (19%)             <ul style="list-style-type: none"> <li>○ County, Coordinated Clinics, Family Voices, Contract</li> </ul> </li> <li>• PH Services \$728,095 (59%)             <ul style="list-style-type: none"> <li>○ Staff, System Contracts, Data Processing, Indirect, Remaining Expenses</li> </ul> </li> </ul> <p><u>MCH Pyramid:</u></p> <p style="text-align: center;">DIRECT</p> <p style="text-align: center;">ENABLING</p> <p><u>PH SERVICES/SYSTEMS</u></p>
<p>Orientation and Family Advisory Council Mentorship</p>	<ul style="list-style-type: none"> <li>• A Family Advisory Council Member Orientation Manual was given to all members along with updates.</li> <li>• SHS staff and existing council members described the purpose and format of the annual Medical Advisory Committee (MAC) meeting to new members.</li> <li>• Moe suggested that everyone should attend the MAC meeting sometime in their term.</li> </ul>

	<p><u>Family Advice from Existing Members:</u></p> <ul style="list-style-type: none"> <li>• It takes two or three meeting to become more active after you learn more what the Family Advisory Council is trying to achieve and how you can help.</li> <li>• The Orientation Manual is very helpful tool.</li> <li>• The Special Health Services (SHS) staff are very well-versed in the programs and can be used as a resource.</li> <li>• Try to find a small something that interests you, and act on it</li> <li>• Take something from every meeting and come up with a few ways to add your input to help others.</li> <li>• It was encouraged to write a family story that can be shared through various methods. <ul style="list-style-type: none"> <li>○ Joe shared that Stella’s Story is about his daughter, and is available on the SHS website, clinics, and the newborn gift box provided to families of a baby with a cleft lip and/or palate.</li> </ul> </li> </ul> <p><u>Suggestions on How to Improve the Council:</u></p> <ul style="list-style-type: none"> <li>• Members could meet before the FAC meeting to discuss the subjects as a group.</li> <li>• The MAC does want to hear from the family members, so more families should attend.</li> <li>• Partner a new member with a staff person or experienced council member to reach out to.</li> <li>• Consider a virtual meeting or conference call to aid with attendance.</li> <li>• It is very helpful to have a list of acronyms, and have staff use the actual name and the acronym when explaining things.</li> <li>• AMCHP is a very helpful and fun national event to attend if families are able.</li> <li>• Family members should get involved reach out to Family Voices to see what is out there of interest for them and Family Voices will assist them in attending an event.</li> <li>• Become an advocate for your child and others.</li> <li>• Taking part in the legislative session makes a difference.</li> <li>• Attend legislative trainings coming up soon to learn how bills get made and passed.</li> <li>• Be a part of the process.</li> <li>• Parent-to-parent partnerships are important.</li> </ul>
Wrap – Up	<p>A farewell to SHS Division Director Tammy Lelm:</p> <ul style="list-style-type: none"> <li>• A card and cake were presented to Tammy from the FAC and SHS staff.</li> <li>• Moe Schroeder presented a card from the Interagency Collaborating Council (ICC) that met this past week which Tammy was unable to attend due to illness.</li> <li>• Evelyn Klimpel presented Tammy with star quilt and a poem, which is something that the Native American people do when someone has touched their lives deeply and is moving on to another time in their life. <ul style="list-style-type: none"> <li>○ Pictures were taken of Tammy with Clifford and Evelyn with the lovely quilt.</li> </ul> </li> </ul>

Reimbursement Forms/ Adjourn	<p>Reimbursement forms/Adjournment</p> <ul style="list-style-type: none"> <li>Forms were collected, and members information and updates were verified</li> <li>Those not in attendance will receive the new Orientation Manual and additional handouts.</li> </ul>
Upcoming SHS Family Advisory Council Meetings Dates	<ul style="list-style-type: none"> <li>January 26, 2019 9:00 a.m. – 12:00 p.m. (Leaders: Family Voices of ND Staff, Tammie Johnson from SHS, and Abbi Berg and/or Garrett Schultz are potential volunteers from the FAC)</li> <li>May 4, 2019 1:30 p.m. – 4:30 p.m.</li> <li>September 14, 2019 9:00 a.m. – 12:00 p.m.</li> </ul>

### SHS Family Advisory Council Recommendation/Review Summary

Meeting Date	Advice and Follow-Up	Action Taken
September 15, 2018	<ol style="list-style-type: none"> <li>The Newborn Screening Program will send out their long-term follow-up survey that is being developed, in an effort to receive further suggestions on improvement from families.</li> <li>Consider having a council member submit a family story that can be utilized in an SHS program or consider an expansion to Stella's Story.</li> <li>Share information with council members from Protection and Advocacy (P &amp; A) during the legislative session to help keep them informed.</li> <li>Provide a list of other councils within the Department of Health, in which family members can get more involved.</li> <li>Invite the lead of the Developmental Disabilities (DD) Council to present, so families can learn more about their work efforts and mission.</li> </ol>	<p>Amy will solicit feedback at January 2019 meeting.</p> <p>Garrett will be presenting his family story at January 2019 meeting.</p> <p>Here is the website to Protection and Advocacy <a href="http://www.ndpanda.org/">www.ndpanda.org/</a> . During the Legislative Session they provide updates and reports on legislative actions.</p> <p>An email was sent to the Healthy and Safe Communities section inquiring about other committees that would allow for family engagement. Any responses received will be shared at the January 2019 meeting.</p> <p>Julie, DD Council, will provide a presentation at the January 2019 meeting.</p>