

**Special Health Services (SHS)
 Family Advisory Council (FAC) Meeting
 September 19, 2020**

Attendance:	
Guest Speakers	Donene Feist, Family Voices of ND
Family Advisory Council Members	Sarah Carlson, Garrett Schultz, Abbi Berg, Amber Cummings, Alakiir Nhial, Liv Fetterman Berger, and Jessica Howling Wolf
SHS Division Staff	Kimberly Hruby, Heather Kapella, Tina Feigitsch, Danielle Hoff, Jaime Conmy, and Amy Burke
Welcome and Introductions	The Special Health Services (SHS) Program Administrator, Danielle Hoff, provided a warm welcome and relayed appreciation for the time devoted for the Family Advisory Council (FAC) meeting and the commitment made by participants to assist the division in its work throughout the year. Introductions were made and new member, Alakiir Nhial, was welcomed.
Last Meeting Follow-Up and Approval of Minutes	<p>Danielle reviewed the agenda items for the meeting and asked for any additional items the group would like to add to the agenda. Kimberly discussed an opportunity for family members to join a Health Equity Committee that meets once a month. Kim attached a handout to the meeting invite which includes a description of the committee along with contact information for family members interested.</p> <p>There were no follow-up items that needed to be addressed from last meeting on May 2, 2020. Minutes from the May 2, 2020 meeting were reviewed, and Danielle asked for a recommendation to approve the minutes. Liv motioned to accept the minutes. Sarah seconded the motion. Motion unanimously carried to accept the meeting minutes as written.</p>
SHS Announcements and Program Updates	<p>Kimberly provided an update to the MCH Block Grant application and virtual review.</p> <ul style="list-style-type: none"> • The application was successfully submitted and accepted for this year. It looked a lot different this year due to COVID and everything being pushed back a bit. • The first virtual review with federal partners will be held the morning of November 5, 2020. Kim invited the family members to join this review if interested as they play a critical role in the MCH Block Grant. Family Members that are interested should let Kim know and she will forward the meeting invite.

- Sarah would be interested in joining the review- Kim will forward the invite.

Kimberly discussed the Newborn Screening (NBS) Quality Improvement (QI) project that is currently underway. Amy Burke, NBS Nurse Consultant, has successfully developed a long-term NBS program. However, many of the processes are still paper based, which is not always the most efficient. The NBS staff relies on the Health Information Network (HIN) to obtain necessary patient information. However, the HIN is only as good as what providers decide to put in. The focus of the QI project is to collaborate with partners from the HIN who are working with providers to ensure they are all consistently inputting in the same accurate data.

Amy added that the NBS program is working on the Critical Congenital Heart Disease (CCHD) QI project in which they are revising the vital records birth certifier worksheet. There are pediatricians and cardiologists that are looking at the current questions on the worksheet and are suggesting any changes. This will assist in determining the number of babies that are being missed or parents refusing the CCHD Screening. They are thinking there is a data entry error, but they will be doing some chart audits from the hospitals to ensure this is in fact the case.

Amy discussed revisions they are making to the NBS brochure and showed the group the current brochure and welcome card. Amy is looking for assistance with coming up with a statement for their NBS brochure regarding long-term follow-up (LTFU) information.

- Abbi suggested the box that includes information that parents may refuse screening could maybe be smaller as it looks larger than the rest of the text on the page.
- It was also suggested to put the LTFU statement under the Abnormal Results box. It could say "If concerns are present, ongoing support may be provided to your family at no cost" This statement can also be added below the statement of Block C.
- Amy mentioned that the number of conditions they are seeing are this year are very low. They are only seeing about half of the amount they would normally see.

Danielle updated the group on the work that is being to address the transition priority and asked the group for any feedback they have on what to include in the toolkit.

- Danielle and Heather are working on updating and revising a transition toolkit that can be sent to pediatricians for more education. The majority of the information in the toolkit is from Gottransiton.org
- Danielle will email the toolkit to the group and they can provide any feedback/suggestions they have.

Family Story: Jessica Howling Wolf	<p>Jessica shared a beautiful video on Benny. Benny was infected with West Nile four years ago and Jessica discussed her story, how it has changed their lives, and how she continues to advocate for Benny and for a vaccination. The group provided their appreciation to Jessica for sharing her story.</p>
Guest Speaker: Donene Feist, Family Voices of ND	<p>Family Voices put together a comprehensive survey to capture the feelings, emotions, and opinions of families of children with special health care needs during the COVID pandemic. It shows there is a lot of need from these families. The group wanted to share their experience they have had with the COVID pandemic.</p> <ul style="list-style-type: none"> • Telehealth and other virtual options for medical appointments have been one benefit during this pandemic as they are still receiving care from home and not putting children at risk. • Obtaining PPE and other supplies, such as masks, disinfecting wipes, and hand sanitizer, is a significant challenge for providers. • It is frustrating to hear “everyone is going to get COVID anyways” and for those differing opinions on mask wearing. • Donene mentioned they received a \$7,500 grant in which they will purchase technology equipment for children to use to have a telehealth appointment that do not have access to a computer/tablet. • Discussed was had on how the pandemic has greatly affected work/life balance along with the mental health of everyone in the family. • It is hard to know that there is no clear end to this pandemic at this time. It gets to be overwhelming as parents have become teachers, therapists, etc. Resources and services that used to be available, such as respite care, is now a challenge. • It is scary that children are regressing. Consistency is key for children to continue to progress. • Donene mentioned that if there is something you are feeling or are struggling with, the FAC is a great group to share these concerns with as they have your back and are your voice.
COVID Discussion	<p>SHS staff are dedicating a significant amount of time geared towards COVID response efforts. Kimberly asked the group if there is anything that families are struggling with or have concerns with regarding SHS programs. SHS staff want to ensure consumers are receiving the needed services.</p> <ul style="list-style-type: none"> • There was a formula issue early in the pandemic where families were not able to get formula they needed. It always worked out as families would donate open/unopened cans. However, initially some families were buying large quantities whereas other families were not able to purchase extra formula to stock up. Although it would be a lot of work, it would have been helpful if WIC would have been able to organize a program to assist families looking for formula to get them through and to take donations from other

	<p>families.</p> <ul style="list-style-type: none"> • There is still an issue with obtaining the necessary PPE and other needed supplies, such as disinfecting wipes, for providers and families. All avenues have been explored such as HAN Assets. Is there a way to get PPE and other necessary supplies through SHS at-cost for families? If SHS could get these items through a DME provider who would be able to bill SHS, this is an option that could be explored. Kimberly will connect with Kim Mertz, Section Chief, to discuss options. • Families need support with obtaining supplies, such as specialty formulas, that are having issues with billing, etc. • Medical providers are going above and beyond. However, there is still trouble combining appointments, such as doing immunizations at an appointment that is already scheduled, to limit the number of times the family needs to see the provider. After asking, many healthcare facilities are not willing to do this, it may be due to insurance and how they are able to bill for appointments. • Some support from Developmental Disabilities Program Managers (DDPMs) seems to be lacking due to the constantly changing guidance.
<p>Administrative Items</p>	<p>Danielle asked the group what they prefer for the format for the upcoming 2021 FAC meetings. Discussion was had that is nice to be in person, especially for the Medical Advisory Committee meeting. However, for those who travel and due to COVID, it is also very nice to do meetings virtually.</p> <ul style="list-style-type: none"> • It was suggested to try for one in-person meeting, possibly the May meeting, and the other two can be virtual. The group was in agreement with this suggestion. This is how we will set up the 2021 meetings.
<p>Closing Remarks/ Wrap-Up and Reimbursement</p>	<p>Danielle asked the group if there were any agenda items they would like to see for the January meeting.</p> <ul style="list-style-type: none"> • It was suggested to ask Caprice Knapp, NDMA Director, if she would be willing to be the guest speaker for the January meeting. SHS staff will reach out to Caprice to see if she would be willing to join. • The Division of Early Childhood (DEC) Conference is virtual this year and will be held on January 21, 2020-January 29, 2020. • The Abilities Expo, an event focused on mobility for children and promotes innovative thinking, will also be virtual this year and will be held on February 26, 2020-February 28, 2020. <p>Kimberly discussed how reimbursement works for our family members. They should expect their \$75 stipend in about 3-4 weeks. These forms will be submitted electronically on behalf of the members.</p>

	Danielle thanked the group for the time they have donated and the dedication they have provided to serve on the FAC. Appreciation was given to all family members and their continued service.
Upcoming SHS Family Advisory Council Meeting Dates for 2021	Saturday, January 9, 2021, 9:00 a.m. – 12:00 noon – Microsoft Teams Saturday, May 8, 2021, 1:30 p.m. – 4:30 p.m. – In-person (if able) and Microsoft Teams Saturday, September 18, 2021 9:00 a.m. – 12:00 noon – Microsoft Teams

SHS Family Advisory Council Recommendation/Review Summary

Meeting Date	Advice and Follow-Up	Action Taken
September 19, 2020	Is there a way to get PPE and other necessary supplies through SHS at-cost for families?	Kimberly Hruby sent an email to upper leadership asking about where families might be able to access PPE from, other than the medical cache that exists for providers. She will share information with the council as received.
	Can the meeting invite for the virtual MCH Block Grant review be sent to interested FAC members and Family Voices of ND?	Kimberly has sent this invite out to the FAC members who expressed interest, as well as additional Family Voices of ND staff.
	Can additional information be sent regarding the Health Equity Committee?	After receiving interest from a few different FAC members, contact information was sent out to the ND DoH Health Equity Director.
	Can the changes to the NBS brochure be implemented?	Amy has brought the suggested changes back to the Newborn Screening Program Director and the Newborn Screening Advisory Council for these suggestions to be implemented.