

**Special Health Services (SHS)
 Family Advisory Council (FAC) Meeting
 January 9, 2021**

Attendance:	
Guest Speakers	Jodi Hulm
Family Advisory Council Members	Sarah Carlson, Garrett Schultz, Alakiir Nhial, Liv Fetterman Berger, Kim Ilse, Moe Schroeder, and Jessica Howling Wolf
SHS Division Staff	Kimberly Hruby, Heather Kapella, Tina Feigitsch, Danielle Hoff, Jaime Conmy, Joyal Meyer, 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 from the Family Advisory Council (FAC). Introductions from the council were made.
Last Meeting Follow-Up and Approval of Minutes	<p>Danielle reviewed the agenda items for the meeting and reviewed the action items that required follow-up from the September 19, 2020 meeting.</p> <ul style="list-style-type: none"> • PPE and supplies through SHS at-cost for families <ul style="list-style-type: none"> ○ Only major resource we have to order PPE is medical cache. Still encourages us to reach out to medical cache to see what they can get. She did send this to Sarah Carlson to look into further. Sarah has mentioned that access to PPE has since improved. Prices have also improved since the beginning of the pandemic. They only item they are still seeing a shortage on would be N95 masks, but they are not seeing a large demand by families for N95 masks. ○ Kim mentioned that SHS staff are also providing all PPE for families if needed when performing clinics and other services. ○ Amy discussed there may be a need for education regarding appropriate masks for families with children with special health care needs. ○ Sarah mentioned that she has seen and heard that family support individuals are being put on the waiting list for the COVID-19 vaccine and family members being vaccinated to protect their children. Kim Ilse echoed what Sarah discussed and said she has been able to get the vaccine to protect her child. • Meeting invite for virtual MCH Block Grant review be sent to interested FAC members and Family Voices of ND

	<ul style="list-style-type: none"> ○ This was sent out to those that were interested in joining the review. ● Information to be sent to those interested in the Health Equity Committee <ul style="list-style-type: none"> ○ Those that were interested in joining the committee contacted Kim Hruby who then sent their contact information to Krissie Guerard. If they have not been contacted yet, they should be shortly. ● Changes to the Newborn Screening brochure to be implemented <ul style="list-style-type: none"> ○ Amy mentioned that all the suggested changes were made, and 20,000 new brochures were ordered. She thanked the council for their valuable feedback. <p>Minutes from the September 19, 2020 meeting were reviewed, and Danielle asked for a recommendation to approve the minutes. Sarah motioned to accept the minutes. Liv seconded the motion. Motion unanimously carried to accept the meeting minutes as written.</p>
<p>SHS Announcements and Program Updates</p>	<p>Kimberly provided an update to the MCH Block Grant application and virtual review</p> <ul style="list-style-type: none"> ● The Block Grant Review was a bit different this year due to the pandemic. Historically, the review is done in Denver and is completed in September. However, this year it was held virtually and was completed in October. This was beneficial to staff and families as they had the opportunity to listen in to the review, which had not been offered in the past. It is the hope that the virtual option continues going forward. ● Some FAC members / Family Voices staff did attend the review. This was helpful as they were able to offer their feedback and expertise. ● Kim highlighted positive feedback that was received during the review and she was happy with how it went. The reviewers did not have any major recommendations for the CSHCH side or within the MCH group as a whole. They have been impressed with the amount of work that is being done by a small amount of staff and funding. SHS has continued with their services, with some modifications, throughout the pandemic, which they were impressed by as well. ● During last Block Grant review, there were two priorities, Medical Home and Transition, that were focused on. Moving forward for the next five years, SHS will drill down and focus on one measure per domain. Transition will be primarily focused on. However, SHS will continue to integrate and address medical home into the work that is being done. Therefore, medical home will not be going away, it will just be intertwined into Transition services that will be done. ● Sarah Carlson was able to join and appreciated the virtual experience. The reviewers were impressed with what ND is able to do to support families. The reviewers were able to see challenges and make recommendations to help mitigate those challenges. It would be great to open the review up to families

to offer feedback on their personal experience with the programs and services. Kim Hruby mentioned that they do try to incorporate MCH success stories in the Block Grant application. It has been brought up in the past to have a tangible project the FAC can work on together. This could be a project the council could work together on to incorporate into the application and represent families. Because attachments can be included in the application, this would be a great attachment to include. Kim discussed it would be great to tie in other MCH priorities to include as well regarding family experiences. Moe is willing to work with other Divisions within the NDDoH to assist with their priorities.

- Moe mentioned that what they did last legislative session was great. Perhaps adding new family stories to this would be helpful. It was greatly appreciated by legislators in the past as it is nice to see a face and read a story. This template could be sent out to the council that could be used for the Block Grant application, legislation, etc.
- Discussion was had on how great ND is doing with the services being offered and family engagement. Although staff is always trying to improve processes and do more, it is important to recognize how well we are doing.

Kimberly provided a brief update on the budget and legislation that is currently occurring.

- First week of legislation started this last week. One major general funds reduction that was proposed within SHS relates to the Fetal Alcohol Syndrome (FAS) Center at UND. Much of the general funds SHS provided went towards research and seeing a small number of patients. This was chosen to be taken out of the SHS budget for the next biennium. This was submitted to OMB and support and then was also supported by the Governor's Office.
- Discussion was had with the Department of Human Services to see if they would absorb this as the FAS work efforts may better align towards the DHS missions around substance use and direct services. They agreed with our thought process but are in the same situation on needing to make a reduction in general funds, so they do not feel they are able to take this on at this time. We will wait and see how this plays out in legislation. Otherwise, the SHS budget will remain relatively the same. There were just a few minor increases such as the funding geared towards claims payments.
- Going forward, budget will be heard on January 14, 2021 in Senate Appropriation. Due to the pandemic, there will be limited seating, so they are asking only the people need to be there attend in person. Folks are able to listen in and testify virtually. Also, folks can go back and watch recordings of hearings if they missed it live. This can be done on the legislative website.

	<p>Kimberly and Amy discussed the status of the 905 forms that were submitted to ND Medicaid by SHS.</p> <ul style="list-style-type: none"> • One form was a formal request for NDMA to cover continuous glucose monitors (CGMs). The other form was a formal request for NDMA to cover metabolic supplements that are necessary for development with individuals with a metabolic condition. Both 905 requests are moving forward into bills. • Alakiir and Tina discussed the financial impact of SHS covering CGMs is having on the budget. There are a few concerns with insulin being administered in the schools. SHS is not having issues with pumps being covered, it is more of the CGMs and associated supplies such as the sensors.
Guest Speaker: Jodi Hulm, ND DHS, Medical Services	<p>Jodi provided a great presentation and overview of Health Tracks / EPSDT. Questions from the council were addressed throughout the presentation. The presentation has been saved on the SHS Teams Link for FAC if members are interested. ESPDT Presentation for Family Advisory</p>
Administrative Items	<p>Kimberly discussed the status of the number of families that are currently serving on the FAC. Because a few families have needed to resign from the council there are several vacancies. If the council knows of a family that would be interested in joining the council, they can apply online through the SHS website.</p>
Closing Remarks/ Wrap-Up and Reimbursement	<p>Danielle reviewed the dates and times for the remaining FAC meetings for 2021</p> <ul style="list-style-type: none"> • Meeting scheduled for May 8, 2021 will be offered in-person and virtual if able with COVID. • Meeting scheduled for September 18, 2021 will be virtual via Microsoft Teams. <p>Danielle thanked the group for the time they have donated and the dedication they have provided to serve on the FAC.</p>
Upcoming SHS Family Advisory Council Meeting Dates for 2021	<p>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</p>

SHS Family Advisory Council Recommendation/Review Summary

Meeting Date	Advice and Follow-Up	Action Taken
January 9, 2021	Kimberly to send out the family experiences template to the FAC to work on and update if interested to be used in the next Block Grant application.	Kimberly emailed out the template to the FAC to take a look at and work on if there is interest from the council.
	Kimberly to send out a list of other MCH priorities, other than the SHS priorities, to the council in case they are interested in partnering with them as well to help with their priorities.	Kimberly sent the document highlighting all of North Dakota's chosen priorities for the next 5-year cycle.
	Provide education to families on appropriate masks for children with special health care needs.	Kimberly emailed out several reputable national resources on information regarding mask wearing and children with special health care needs to the FAC to view.