

Special Health Services (SHS)
Family Advisory Council Meeting
January 29, 2022

Attendance:	
Family Advisory Council Members	Sarah Carlson, Moe Schroeder, Alakiir Nhial, Shasta Held
SHS Division Staff	Jaime Conmy, Tina Feigitsch, Kimberly Hruby, Danielle Hoff, Heather Kapella, Amy Burke, Joyal Meyer
Welcome and Introductions	The Special Health Services (SHS) Division Director, Kimberly Hruby, 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>Kim reviewed the agenda items for the meeting and reviewed the action items that required follow-up from the September 2021 meeting. These action items were all followed-up on.</p> <p>Minutes from the September 2021 meeting were reviewed, and Kimberly asked for a motion to approve the minutes. Sarah motioned to accept the minutes. Moe seconded the motion. Motion unanimously carried to accept the meeting minutes as written.</p>
Family Story	The family story was postponed due to illness.
MCH Workplan Activity Update	<p>Kim introduced Heather and Danielle to provide an update on the Maternal and Child Health (MCH) priorities:</p> <ul style="list-style-type: none"> • Basic Information Regarding the MCH Block Grant <ul style="list-style-type: none"> ○ Every year a comprehensive application for the MCH Block Grant is completed, and funding is disseminated based on the number of children in poverty within the state. At least 30% of the Block Grant funding needs to be for Children with Special Health Care Needs (CSHCN). ○ The application was successfully submitted on September 1, 2021, and SHS had the opportunity to highlight programmatic activities that are being worked on, especially in key priority areas.

- CSHCN Domain Priority: Transition from Pediatric to Adult Health Care
 - Working on strategies to ensure families are actively engaged and understand the importance of discussion transition early.
 - Danielle discussed how transition can encompass a variety of factors, such as ensuring that the family is set up with a physician familiar with special health conditions, ensuring the youth has the ability to advocate for themselves when visiting the doctor, etc.
 - Family Voices of ND is developing a transition curriculum, and Heather and their Director, Donene Feist, will be presenting together at the Power Up for Health Conference in August 2022.
 - Working on strategies to improve transition discussions with pediatric medical providers.
 - Approximately 85 pediatricians across the state received a transition toolkit in the mail, which included a letter on the importance of addressing transition and various tools from the National Center of Excellence, Got Transition!, that providers can utilize in their practice.
 - Working on strategies to improve the transition discussion by school health professionals working with youth.
 - SHS Program Administrators, Heather and Danielle, have created a new educational PowerPoint that can be utilized by school professionals to begin the discussion about transition with the youth they are working with.
 - This PowerPoint is currently in the review state and should be available soon.
 - Since not all schools might have staff equipped to have these discussions, Danielle and Heather are also exploring opportunities to visit schools to provide this education.
- Establishing Activities for the Upcoming Year's Plan:
 - Year 3 activities will be drafted soon, and SHS will be seeking input from families, including the Family Advisory Council, to provide feedback on activities that should be occurring.
 - Virtual meetings will likely be taking place, and members should be anticipating an invite from Danielle or Heather.
- Current Suggestions from the Family Advisory Council:
 - Sarah suggested collaborating with Vocational Rehabilitation Services in the ND Department of Human Services.
 - Danielle relayed that some communication has taken place with certain members of their team, but this will continue to be explored and followed-up on as a potential key activity. The contact person for this was recommended as Cheryl Anderson. Cheryl also has

	<p>previous experience with the State Council on Developmental Disabilities and had helped compose a transition guidebook years ago.</p> <ul style="list-style-type: none"> ▪ Moe relayed that there is also a new director of Vocational Rehabilitation that might be a good partner to include in upcoming workgroup meetings for development of annual plan activities. <ul style="list-style-type: none"> • Adolescent Health Domain: Priority to improve Adolescent Well-Visits: <ul style="list-style-type: none"> ○ Heather is currently the Adolescent Health Coordinator/State School Nurse Consultant assisting the Division of Family Health and Wellness to improve adolescent well-visit rates. ○ New grantees have been identified for smaller 6-month grants to move this forward. This was an exciting opportunity to engage new partners, including a recently formed Youth Advisory Board conducting a social media campaign. • State Priority: Implement State Mandates: <ul style="list-style-type: none"> ○ Amy and Joyal are tasked with ensuring that our work around state mandates are documented in the annual Block Grant Application. <ul style="list-style-type: none"> ▪ Examples of state mandates within SHS include but are not limited to: Newborn Screening, implementation of a metabolic food program for children with Phenylketonuria (PKU) or Maple Syrup Urine Disease (MSUD), etc. ▪ Discussion took place regarding educational materials or photos that are often used to educate about PKU and newborn screening. Joyal relayed that she appreciated the feedback from the council as these were fresh perspectives.
<p>SHS Administrative Items</p>	<ul style="list-style-type: none"> • Assistance with Member Recruitment and Decisions with Current Membership: <ul style="list-style-type: none"> ○ The council was requested to send any ideas for potential new members to Jaime Conmy (jlconmy@nd.gov). Current guidelines allow space for 10-12 members on the Family Advisory Council. Terms are for two years. ○ The council agreed that current guidelines are fair, and members who have missed 3 concurrent meetings without notification should be thanked for their time but released from their current term on the council. ○ A recommendation from the council to increase membership applications is to include a 1-page fact sheets for families attending multidisciplinary clinics or applying for the Financial Coverage Program. • Potential Items for Medical Advisory Meeting in May:

	<ul style="list-style-type: none"> ○ A recommendation was to discuss the need for primary physicians to relay important information (e.g., newborn screening results) to families rather than delegating that to a nurse. ○ Another recommendation was to combine the Family Advisory/Medical Advisory Council Meeting in May. The group unanimously agreed upon this recommendation.
<p>SHS/NBS Program Updates</p>	<ul style="list-style-type: none"> ● Changes to Financial Coverage Program: <ul style="list-style-type: none"> ○ In December 2021, SHS dropped the threshold for the Financial Coverage Program from \$20,000/child per eligibility year down to \$5,000/child per eligibility year. ○ Tina gave a breakdown to the council on how SHS arrived at this decision based upon current spending and high-cost conditions. ○ Most families do have insurance but are considered under-insured. ○ If families do not have insurance, SHS is providing care coordination to help families obtain private insurance, waived services, coverage through ND Medicaid, etc. It is also hoped that care coordination will improve further with the ND DoH/DHS integration in September 2022. <ul style="list-style-type: none"> ▪ Moe recommended further referrals to utilize the Medicaid Buy-In Program, which is under-utilized by families. ● Newborn Screening Updates Regarding Long-Term Follow-Up: <ul style="list-style-type: none"> ○ The new process utilizing a question package within the Health Information Network (HIN) has been implemented and is working well. ○ Amy and Joyal agreed to demonstrate this for the council at a meeting where more time allows.
<p>Closing Remarks/Wrap-Up</p>	<p>Kim and Jaime will get the reimbursement forms submitted so families receive their reimbursement.</p> <p>Kim thanked the group for the time they have donated and the dedication they have provided to serve on the Family Advisory Council.</p>
<p>Upcoming SHS Family Advisory Council Meeting Dates for 2022</p>	<ul style="list-style-type: none"> ✓ Saturday, May 7, 2022, 8:30 a.m.-12:00 noon (Combined Medical and Family Advisory Council Meeting) – Microsoft Teams ✓ Saturday, September 17, 2022, 9:00 a.m.-12:00 noon – Microsoft Teams

SHS Family Advisory Council Recommendation/Review Summary

Meeting Date	Advice and Follow-Up	Action Taken
January 29, 2022	Explore collaborations with entities such as Vocational Rehabilitation, who might be able to help with transition activities within the school setting.	Communication has already taken place with Barb from Vocational Rehabilitation, but Danielle and Heather will reach out to Cheryl Anderson before working on Annual Plan activities for the next year.
	Develop a 1-page fact sheet regarding the Family Advisory Council that could be disseminated at clinics, application appointments, etc. to increase membership.	This has not been completed but is currently in progress.
	Place an item on the 2022 Medical Advisory Agenda to discuss the importance of not delegating important phone calls to families, as these should be coming from the medical provider and not the nurse.	This item has been placed on the list for May's agenda.
	Consider combining May's Medical Advisory and Family Advisory Council meetings rather than holding two separate meetings.	This has been completed. The meeting invite for Family Advisory has been cancelled and all members are invited to attend the morning meeting with the Medical Advisory Council.