

Special Health Services (SHS) Family Advisory Council (FAC) Meeting September 18, 2021

Attendance:	
Guest Speakers	Nick Walker
Family Advisory Council Members	Sarah Carlson, Alakiir Nhial, Joe Liccini, Moe Schroeder and Smriti Bista
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) 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.
SHS / Title V Overview	Because the FAC has had several new members join, and there is a lot of information that is covered regarding the various SHS programs, Kim provided an overview of the Division of SHS and the various programs and services that are coordinated and carried out within the Division.
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 May 2021 meeting. These action items were all followed-up on.</p> <p>Minutes from the May 2021 meeting were reviewed, and Kimberly asked for a recommendation to approve the minutes. Sarah motioned to accept the minutes. Joe seconded the motion. Motion unanimously carried to accept the meeting minutes as written.</p>
SHS Announcements and Program Updates	<p>Kim highlighted the program updates from SHS. These updates included:</p> <ul style="list-style-type: none"> • MCH Block Grant Review <ul style="list-style-type: none"> ○ Every year a comprehensive MCH application for the 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.
- The review of the application will be held virtually on December 14, 2021.
- FAC members who are interested in sitting in on the review are more than welcome to do so. It is helpful to have families and family partners attend to discuss and provide input on family engagement.
 - Moe volunteered to attend the review.
 - If other families or partners want to attend, contact SHS staff for the virtual invite.

- Department of Health and Department of Human Services integration
 - Legislative mandate that these two departments will be merging into one agency that will be completed by September 1, 2022. Staff from both departments just recently attended a meeting and were able to meet the consulting company that was hired to lend their expertise and assist with a successful merge.
 - SHS has been vocal about wanting a place at the table and wanting our voices to be heard throughout the merge process. It is the hope that if there is a meeting with SHS staff, that families and partners can be brought in to provide their input and feedback as well. As more is learned, SHS will keep the FAC updated.

- A meeting was held with Jodi Hulm regarding the Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) program to discuss certain cases where treatments/services were not being covered by EPSDT.
 - They do have a review process for pediatric claims that come into ND Medicaid that evaluates medical necessity. She encouraged SHS staff that if they are seeing specific cases that are being questioned, that staff reach out to Jodi with the case details for a re-evaluation.
 - There have been quite a few cases that have been sent over to Jodi to evaluate why it is not being paid by EPSDT. It has been found that the providers are not submitting correctly or not submitting prior authorizations properly. In turn, Tina and Jaime have been working with the providers to ensure they are submitting things correctly, so they can be paid. As of now, even the cases that have been worked on with the submission errors, have not yet been paid. However, this is still being worked on and followed-up on.
 - Non-covered services, such as genetic testing, will be looked at and SHS staff will possibly submit another 905 form to get those services covered. Although it tends to be a lengthy process, SHS staff have had success doing this to get things added to the plan. The topic of getting genetic

	<p>testing covered will be an agenda item for the upcoming NBS advisory meeting as well. SHS is having a hard time paying these genetic testing claims as well with issues with the payment system. Tina and Jaime will meet with Jodi again to discuss further and brainstorm what is occurring with these issues.</p> <ul style="list-style-type: none"> ○ During legislative session, it was determined that an EPSDT study will be required to be completed.
<p>Walker Family Story</p>	<p>Jaime introduced Nick Walker to the group as the guest speaker to share his family story:</p> <ul style="list-style-type: none"> ● Nick introduced himself and provided the story of his daughter who was born with a cleft palate. He discussed the various surgeries she had and how great she is doing now. ● His message to the FAC was that regardless of diagnosis, just love your child and their talents and everything will be okay. The care and services his family received through the state, including the Cleft Lip and Palate clinic team, got their family through and he greatly appreciates everything SHS has done for him and his daughter.
<p>Administrative Items</p>	<p>Kim discussed how FAC membership is getting smaller as families have had to resign their position for various reasons over the last year. The Council can accommodate up to 12 members, and currently there are 7 members on the FAC. Therefore, SHS is in search of new members that would be interested in joining the FAC. If current members have any ideas of families that would be interested in joining the FAC, they are able to apply online on the SHS website. It is a very simple application, and they can reach out to SHS staff with any questions.</p>
<p>SHS / NBS Updates</p>	<p>Kim provided an overview of other updates within the Division:</p> <ul style="list-style-type: none"> ● Dr. Joan Connell has resigned as the DoH Chief Field Officer but has agreed to stay on as the SHS Medical Director and NBS. A new contract with her has been created and SHS is working to finalize the final details of the contract. She will be serving a two-year contract, and it will be renewed every two years. ● Joyal provided an update on their CQI grant that they have had for two years and have received continuation of that grant for another year. They also just recently received a HRSA grant that will help with long-term follow-up needs. They are going to be building a care coordination module that connects with the ND Health Information Network (ND HIN). They are working to move away from faxing medical records and scanning information into charts and moving forward on sharing patient data electronically. NBS has been working with NDIT to move forward.

- Joyal provided screenshots of what the care coordination module will look like and the various functionalities it will have. She reviewed the various goals they have established and strive to meet following the two-year grant that ends in 2023.
- Amy added that they may reach out to the FAC for input on the family perspective to ensure the information that is being collected and questions that are being asked are important and getting at identifying what the needs are.
- The care coordination module, at this time, is for children in ND that were identified through the NBS program. It is the hope this will help assist with building a medical home for these children and ensure families are aware of what a medical home is.
 - Facilities and providers have various definitions of medical home. There are some organizations that have been certified in medical home or nationally recognized by meeting established criteria. However, there are other organizations that may be implementing and practicing medical home standards but are just not nationally recognized.
 - Education will be provided to providers on medical home as well during the project. It is the hope that this is a step on the right direction to have a one-stop-shop portal for medical home. The ultimate goal is to enhance communication among providers that are offering care and services to the same child.
- Tina discussed several changes that have been implemented within the Financial Coverage program.
 - Applications continue to rise, and changes were implemented to streamline processes and reduce administrative work.
 - Historically, all families would qualify for the Financial Coverage program, but some may have had significant monthly cost-shares that needed to be exhausted prior to SHS being able to assist with coverage. It was determined that there will now be a cap to the cost share of \$3,000, which is an amount that is possible for families to meet. However, specific cases can be looked at if families wish to stay on the program, even with a high cost-share as they feel that amount could met.
 - Currently, it is possible for a child to be on the Diagnostic program for one condition and the Treatment program for another condition. Because the Diagnostic program does not look at income and the Treatment program does, this was causing issues in claims for families that have a cost-share on the Treatment program. The system wanted to apply the cost-share to all claims, including diagnostic. Now, families that are on both programs and have a cost-share will now have

	<p>a waived cost-share while the eligible diagnostic condition is still open. Tina will be monitoring the Diagnostic program closely to determine if/when a diagnosis has been ruled out/confirmed. Once this occurs, the cost-share will go back into place.</p> <ul style="list-style-type: none"> • Kim discussed how accessing a larger number of families and building partnerships with various healthcare organizations and other providers, is causing an increase in the number of referrals that are coming in, resulting in a significant increase in the amount of payments being made through claims. <ul style="list-style-type: none"> ○ High-cost clients, who more than likely will be meeting the maximum \$20,000 annual cap, continue to rise. Currently, there are 4 clients who are considered high-cost. The concern is, if we continue at this rate, SHS potentially will have no money left to help families. ○ SHS staff are going to take a closer look and analyze where the money is being spent. It is known that pharmacy claims have quadrupled, it is important to look at what is causing this. Kim asked the group to just think about programmatic or procedural changes that could be impactful. ○ With flat funding and increased spending at this rate, while always hard, some options and process changes will need to be considered. Several ideas will be looked at and explored to reduce spending, such as looking at exclusions on what can be covered for a certain condition, pharmacy exclusions, lowering our maximum cap, converting the Cardiac Care for Children’s program to the Diagnostic program, etc. ○ It was discussed that possibly working with private insurance staff, such as their social workers, may be helpful to determine what could potentially be covered that families may not know about. ○ Once claims data is analyzed and underlying information is identified, SHS may reach out to FAC and MAC for feedback and input. ○ Discussion was had that before kids turn three and are not able to get on the DD waiver, could potentially look at the Medically Fragile waiver. Because Medically Fragile waiver slots are determined by legislators, families always have the option to contact their local legislators to discuss expanding those slots. There was discussion on issues on getting connected to the right person regarding the 1915(i) waiver. It was suggested to reach out to Krista Fremming, DHS, to determine who is the right contact to reach out to.
<p>Closing Remarks/ Wrap-Up and Reimbursement</p>	<p>Kim asked the group about a family story for next meeting. SHS is looking for a volunteer who is willing to share their story with the group. The story does not have to be from a member, it could be someone who has received services from SHS in the past. Members can reach out to SHS staff if they can think of someone or would like to</p>

	<p>volunteer themselves. Family members then provided updates on their families and how things were going for them.</p> <p>Moe shared that the University of Minnesota has a Single Ventricle Clinic, which is a coordinated treatment clinic which includes stress test, ultrasound, heart catheterization every 2-3 years, etc. Moe wanted to make the group aware of this opportunity for the cardiac population.</p> <p>Sarah shared the Division of Early Childhood, that goes from birth to age 8, is holding a virtual Conference next week. There is also a PICU Continuity Conference next week, which Sarah is speaking at, to help set standards for kids with lengthy hospital stays and what can be prescribed to prevent future hospital visits or enhance hospital visits. There is a Neurodisability Conference that has a family component to every subject These will be held once per month.</p> <p>Joe wanted to make the group aware that the TriCare electronic portal has been very helpful managing and accessing medical information and could be a good model to look at while NBS builds their care coordination module.</p> <p>Kim reviewed the upcoming meetings that will be held virtual. The plan is to look into holding the next May meeting in person or hybrid if able. 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 FAC.</p>
<p>Upcoming SHS Family Advisory Council Meeting Dates for 2022</p>	<ul style="list-style-type: none"> ✓ Saturday, January 8, 2022 9:00 a.m. – 12:00 noon – Microsoft Teams ✓ Saturday, May 7, 2022 1:30 p.m. – 4:30 p.m. (following Medical Advisory) – Platform TBD

SHS Family Advisory Council Recommendation/Review Summary

Meeting Date	Advice and Follow-Up	Action Taken
September 18, 2021	Invites for the virtual Block Grant Review to be emailed out to any FAC member interested in joining.	Outlook invites were sent to Family Advisory Council members who had expressed interest in attending.
	Recommendations for new FAC members can be sent to SHS staff.	One recommendation was received within the SHS office and forwarded to Jaime Conmy, Family Advisory Council lead, to reach out.