

Children's Special Health Services
Family Advisory Meeting
May 3, 2014

Attendance:	
Family Advisory Council members	Cheryl Klee, Carla Peltier, Lisa Beckman, Moe Schroeder, Laura Roberts, and Lori Hanson (phone).
CSHS Division staff	Tamara Gallup-Millner, Devaiah Muccatira, Kim Hruby, Tammie Johnson, Kodi Berg and Carrie Tate
Other	Dr. Joan Connell, MD, Children's Special Health Services Medical Director
Welcome/Introductions/Announcements	<p>Tammy welcomed participants to the meeting and introductions were made, including introduction of a new CSHS staff member, Kodi Berg, the Autism Database Administrator.</p> <p>Family Advisory Council member updates:</p> <ul style="list-style-type: none"> • Moe shared bracelets for MPS Awareness Day. • Laura relayed that Clay took 4th at state in wrestling and Cole is graduating and will attend BSC this fall. • Lori shared that her daughter Alicia is getting married on August 3rd. • Tammy relayed that she will be a grandma for the second time this summer. <p>The following video was shared with the council: http://www.kare11.com/story/news/features/2014/04/01/bree-hanson-heart-transplant-junior-prom-birthday-bedside-organ-donation/7182579/</p>
Follow-up from February 2014 Meeting	<ul style="list-style-type: none"> • February 2014 minutes were accepted as written. Members relayed they liked the new format and found them easier to read. • Tammy provided CSHS updates in response to the advice from the February 2014 meeting recorded on the Recommendation/Review form. • The following suggestions for a CSHS quality improvement project were discussed: <ul style="list-style-type: none"> ○ Encourage more communication between county staff (eligibility and social work). Referrals can be difficult because of privacy/confidentiality concerns without a signed authorization. There is also high staff turnover so knowledge transfer may be sporadic. CSHS staff should continue to try to train county staff on a regular basis. • Moe and Cheryl discussed the update on the Family Advisory Council Data Story Profile project. <ul style="list-style-type: none"> ○ The letter packet that was created has been taken to the DoH public information officer and distributed at this meeting. ○ Council members felt the information provided was clear and easy for a family to follow.

	<p>They encouraged sharing of positive stories rather focusing only on needs. The intent is not to lobby, but rather showing connections with CSHS.</p> <ul style="list-style-type: none"> ○ The goal of this project is to share stories that depict the values of CSHS in North Dakota. It was recommended that legislative specific information and personal contact information such as phone numbers be taken off to make it more generically useful for a variety of purposes (e.g., include in legislative messages, on the CSHS website, and in data-related publications, etc.). ○ These letters are written to benefit other parents going through similar situations. Members would like the focus to be on CSHS vs. all of Title V. When completed, the letters would go to a liaison on the Family Advisory Council or to a CSHS staff member. A DoH authorization is needed for CSHS to utilize the stories. ○ Staff suggested that CSHS could have a booth at the public health day during the legislative session and hand out stories to the legislators. ○ Moe will make needed updates and forward them to Kim who will send revisions to the public information officer in the Department of Health for review. ○ Moe will connect with other family volunteers to solicit stories.
2014 Medical Advisory Council Meeting	<ul style="list-style-type: none"> ● 2013 Medical Advisory Council meeting minutes were distributed. ● Dr. Connell summarized the highlights of the 2014 Medical Advisory Council meeting. Family advisory council members, Moe and Cheryl, attended. <ul style="list-style-type: none"> ○ DoH/CSHS updates were given. ○ Medicaid – Julie Schwab talked about Medicaid waivers and the Affordable Care Act. Approximately 3200 families went from Medicaid to CHIP. With the ACA, it's unclear whether CHIP will be reauthorized as it ends in 2015. It was noted that Julie Schwab is a big supporter of Medical Home. Dr. Connell mentioned that there is more than one way to get certified for medical home but reimbursement continues to be challenging. North Dakota needs to assure a peds-friendly approach to medical home certification. ○ Newborn screening follow up and Bettermilk - CSHS and DoH updates were provided, including information on newborn screening fee increases. Better Milk may be offered as a formula option if the supplier will lower the price as it's currently about three times the cost of other PKU formula. ○ Medical eligibility – More work is needed to finalize the CSHS equipment policy. ○ Financial eligibility – For the Cardiac Care Program, pacemaker checks will be moved under treatment services which requires income eligibility to be consistent with other conditions. ○ Autism – Diagnostic issues were discussed as well as the upcoming ASD conference on October 20-22, 2014.

	<ul style="list-style-type: none"> ○ New staff members found the Medical Advisory Council meeting very informative. Families who attended were important contributors and their input was informative.
MCH Block Grant	<ul style="list-style-type: none"> ● MCH Block Grant review is August 21, 2014 in Denver, Colorado. A request was made for Family Advisory Council volunteers to review the written block grant application prior to submission and/or attend the actual federal review via videoconference in Bismarck <ul style="list-style-type: none"> ○ Moe is a possible volunteer to review the grant and/or attend the review. ○ Federal MCH 3.0 update - Staff relayed that new grant guidance will be coming out within the next year. No specifics have been received from the federal level. A policy call is scheduled for May 5, 2014. ● Council members filled out anonymous Family Participation ranking forms and turned them in. ● Tammy conveyed that they continue to try to get public input to ascertain needs and priorities for the MCH Block Grant. She asked for any suggestions on what the state could do differently. ● Devaiah provided an update on the electronic survey that was conducted. This year there were 149 responses over a four-month period. Council members thought that they had filled out this survey. ● Tammy asked for any input on how to get more responses from underrepresented population and how to make it more user/family friendly. <ul style="list-style-type: none"> ○ Council members suggested: <ul style="list-style-type: none"> ▪ Sending the survey to the special education Directors. ▪ It was felt that some families might not have time to fill out this survey. ▪ Do more than just send the electronic survey as many emails get overlooked. ▪ Go to tribal communities and get feedback. Involve cultural brokers. Deal with issues of mistrust. ○ Devaiah and Tammy discussed important focus areas: access to services, mental health, awareness about special needs and services, insurance, and care coordination. Tammy asked council members for input on suggested draft plan activities for the upcoming year. <ul style="list-style-type: none"> ▪ Council members recommendations follow: <ul style="list-style-type: none"> ● CSHS is doing activities in all these areas. It's reassuring to know CSHS is doing the right things. ● Families may not know what they don't know, especially if using walk-in clinics. Continue to get the word out and promote awareness. ● Electronic surveys are not always the best approach. ● In other states, they hire parents who understand the system and help other families. Employ experienced parents in medical home settings. ● Increase home visitors and school nurses. ● People may be aware but just choose not to participate.

<p>CSHS Program Updates</p>	<ul style="list-style-type: none"> • CSHS staff gave “round robin” administrative reports, which highlighted key work activities this quarter: <ul style="list-style-type: none"> ○ Kim reported working on the Autism state conference, adding an additional Bismarck cleft clinic, and that EHDI is working on a quality improvement project to address hearing screening with home births. ○ Tammie reported working with a community of practice subcommittee to develop a brochure for transition-aged youth, which will be going to print fairly soon. She also attended the Heartland conference in Kansas City Missouri. <ul style="list-style-type: none"> ▪ Council member Laura would be interested in a copy of the transition brochure. Other discussion included apps on phones and accessible information for visually impaired. ○ Devaiah has been monitoring birth defects data, is cross walking ICD 9 codes with ICD 10 codes, has developed seven outcome measure fact sheets for the state of ND, and is working on CoIIN and the Title V needs assessment. ○ Kodi is working on the development of the Autism Spectrum Disorder Database. She needs to establish the criteria for who is qualified to diagnose autism with the help of an expert panel. <ul style="list-style-type: none"> ▪ Council members had questions regarding the criteria and how CSHS will reach out to get people involved the panel. Council members suggested reaching out to autism groups. Tammy requested that any specific names be emailed to her.
<p>Housekeeping Items</p>	<ul style="list-style-type: none"> • The bylaws were distributed and reviewed. <ul style="list-style-type: none"> ○ Council members agreed that no changes were needed • Tammy reviewed membership terms that end after the May 2014 meeting with the following responses: <ul style="list-style-type: none"> ○ Lisa – will get back to Tammy with answer ○ Lori – yes ○ Laura – yes ○ Cheryl – yes ○ Moe – yes ○ Carla – will need to be contacted
<p>Reimbursement Forms/Adjourn</p>	<p>After members submitted reimbursement forms, the meeting was adjourned.</p> <p>The Family Advisory Council meeting that was scheduled for Saturday, August 16, 2014 was cancelled due to projected low attendance. The next Family Advisory Council meeting is scheduled for Saturday, November 15, 2014 from 9:00 a.m. to 12:00 p.m.</p>

CSHS Family Advisory Council Recommendation/Review Summary

Meeting Date	Advice	Action Taken
May 2014	<ul style="list-style-type: none"> ○ Encourage more communication between county staff (eligibility and social work). Referrals can be difficult because of privacy/confidentiality concerns without a signed authorization. There is also high staff turnover so knowledge transfer may be sporadic. CSHS staff should continue to try to train county staff on a regular basis. ○ Council members had questions regarding the criteria and how CSHS will reach out to get people involved the Autism Expert Panel. Council members suggested reaching out to autism groups. ○ Council members suggested these strategies to increase survey participation: <ul style="list-style-type: none"> ▪ Sending the survey to the special education Directors. ▪ It was felt that some families might not have time to fill out this survey. ▪ Do more than just send the electronic survey as many emails get overlooked. ▪ Go to tribal communities and get feedback. Involve cultural brokers. Deal with issues of mistrust. 	<ul style="list-style-type: none"> ● A training event was held in September, in which importance of appropriate referrals and communication were emphasized. CSHS plans to hold trainings for county staff annually, and keep them informed of other opportunities for learning throughout the year. ● After careful deliberation amongst CSHS staff, the Autism Panel consisted of representation from state agencies, medical providers, and family representation. ● No progress since no other surveys have been completed. But this will be considered during other upcoming projects.