

**Children’s Special Health Services
Family Advisory Council (FAC) Meeting
February 21, 2015**



Attendance:	
Family Advisory Council members	Joe Liccini, Cheryl Klee, Moe Schroeder (phone), Sarah Carlson, Jennifer Restemayer, Evelyn Klimpel, Lisa Beckman, and Lori Hanson.
CSHS Division staff	Tamara Lelm, Kim Hrubby, Melissa Evans, Devaiah Muccatira, Tammie Johnson, Kodi Pinks and Carrie Tate
Welcome/Introductions/ Announcements	<p>Tammy warmly welcomed all to the meeting. Introductions were made and updates provided by those attending.</p> <p>CSHS announcements included the upcoming Pathfinder Conference April 9-11, 2015 in Bismarck, Family Voices Parent Leadership Institute June 5-7, 2015 in Edgeley, and the Autism Conference October 21-23, 2015 in Fargo. If anyone has suggestions for break out speakers for the Autism conference, please pass them on to Kim or Kodi.</p> <p>Moe attended the AMCHP conference in January and was asked to join as the chair for the Family Leadership Committee. She needs to come up with a work plan for family involvement for all Title V populations, not just children with special health care needs.</p> <p>There was a request for a volunteer for a Family Advisory Council representative to attend the Medical Advisory Council meeting on May 2, 2015 from 8:30-12:00 noon. Moe, Sarah, and possibly Lori are interested in attending.</p>
Follow-up from November 2014 Meeting	<p>Updates for the membership list include: A spelling correction for Sarah as she has an “h” at the end of her name. Jennifer requested her current email address and work phone be removed, as she accepted a new position and will be moving to Fargo. Her new email address is: Jennifer_restemayer@yahoo.com</p> <p>The November 2014 meeting minutes were accepted as written after a minor correction was made regarding approval of the minutes.</p> <p>Staff reviewed advice and actions taken from the November 2014 meeting and received additional feedback from FAC members. Suggestions on how better to inform families regarding changes with maternal child health block grant included the following:</p> <ul style="list-style-type: none"> • Staff could follow-up with Donene about hosting a Family Voices topical call. • Staff could present at the family leadership institute that will be held in June. Moe is in charge of the agenda. • Staff could share information at the Pathfinder conference. If another “talking circle” is held, it would be a good

	<p>opportunity to connect with Native American parents.</p>
<p>Legislative Update and Discussion</p>	<p>Staff relayed it's been a very busy legislative session. Three bills the division is following closely include:</p> <ul style="list-style-type: none"> • HB 1004 Department of Health budget – The Governor's executive budget for the Health Department was first reviewed by the House Appropriations Committee. Legislators conducted a detailed review and made suggested amendments. The CSHS flat funded budget was not changed. No additional revenue is expected as the division did not have any approved optional budget requests. Some reductions in contracts for the 2015-2017 biennium are anticipated if no additional revenue is received. • SB 2176 Autism database - An expert panel recommended changes to the original bill that was passed in 2013. Kodi drafted new bill language to address identified areas of concern (e.g., qualified reporters and their designees, physical evaluation, etc.). The bill has passed in the Senate. <ul style="list-style-type: none"> ○ Jennifer inquired about the database and the waiver. Kodi responded that the database and waiver program are in two different departments and are separate. As for needing permission from the families, Kodi replied that reporting is mandatory, so permission will not be needed. However, as a best practice, CSHS will promote informing families. Kodi is currently developing education materials for families and providers. Before they are printed, they will be brought and shared with the council. Council members recommended informing and involving families along the way as the database is developed and collaborating with DHS on diagnostic services that will support ASD database reporting. • SB 2334 Newborn screening bill - Tammie informed the council that initially this bill addressed housekeeping changes and content reflecting current and best practices with newborn screening. However, CSHS received legislative enquiries regarding potential changes with the portion of the bill that addressed the metabolic food program for individuals with PKU and MSUD (e.g., expand coverage for males through age 44). CSHS responded to several information requests but amendments addressing the metabolic food program were not included in the bill that passed in the Senate. <p>A comprehensive tracking grid is maintained in the Community Health Section with many other MCH/CSHCN-related bills (e.g., tobacco, domestic violence, TBI, behavioral health, oral health, home visiting, autism, etc.). Council members indicated they were also following bills this session (e.g., oil impact and for providers, medical marijuana issue, etc.).</p>
<p>Updates</p>	<p>Department of Health/CSHS Programs</p> <ul style="list-style-type: none"> • <u>ASD database update</u> – Main work activities recently have focused on drafting ASD database bill language, drafting administrative rules, and revising the ASD report form. Kodi informed the council that the ND form is mostly based on New Jersey's forms. An electronic version of the report form will be available online. CSHS met with staff from the

Attorney General's office about the administrative rules and received feedback on suggested changes. The administrative rules require public input and will have to be taken to the State Health Council. . If SB 2176 passes, Sarah asked when the database will start. Kodi responded that she hopes to have it running this summer. Sarah also asked whether the expert panel will be gathered again. Kodi responded that it was a costly meeting, but she does plan to keep in contact with the members from the panel and will continue to get their input as needed. FAC members suggested other groups CSHS should connect with including Tribal Social Services, providers, agencies, larger associations/organizations, NDCPD, and early intervention staff. Sarah also suggested that it might be a good idea to get the employment information from adult individuals with autism. It was also recommended that CSHS anticipate how "teams" with multiple mandatory reporters should report into the database.

- CSHS applications for funding (grant awards/contracts for 2015-2017) – CSHS currently funds multidisciplinary clinic, care coordination, family support, and medical home projects. Changes are anticipated considering new federal priorities for CSHCN (medical home and transition) and resources available for other state mandated services. Family Advisory Council input would be helpful as decisions are made.
 - Council member Jennifer commented that the family support piece is an area of need. Come July 1, 2015, she is unsure of what family support will look like as there is no guaranteed funding in place. Council member Moe commented that she is worried with some of the testimony she has heard this legislative session. Tammy reassured the council that family support is still a valued focus area for the division and that there might also be family support funding in the Department of Human Services budget bill.
 - Tammy relayed that in future, CSHS would like to target three main areas – family support (parent to parent), clinics, and system pieces (medical home and transition). The care coordination contract with Grand Forks Public Health would likely not be funded again. The division has identified a need for more state-level family consultative time that would need to be included in the family support project area. Timeframes may be changed to align with the federal fiscal year. The PRS system will also be used for submission. FAC members were asked if they have other suggested areas where the division should target funding. Council members indicated the following:
 - Council members agreed that parents supporting parents is very important and a priority as is helping families navigate systems.
 - Sarah moved to approve the new approach with contracts and Lisa seconded the motion. Overall members agreed although Jennifer was unsure and wanted more information before making a final decision.

- CSHS publications – CSHS has updated, developed, or acquired some new publications, which are listed below. Most are available online as well.

- CSHS Brochure
- 2015 Clinic Directory
- Healthcare Coverage Options Brochure
- Complex Dental Conditions Resource Booklet
- 7 Data Briefs from the 2009/2010 NS-CSHCN
- Car Safety Brochures from the Division of Injury Prevention and Control

Suggestions on dissemination included:

- Possibly give to the CSHS County Social Services workers to disperse to families.
- Share with Pathfinder, Family Voices, and other family support organizations.
- Ronald McDonald Care Mobile, Bridging the Dental Gap, or to those that are doing sealants in schools for the dental resource booklet.
- School nurses would be a good one to get information out to those that need it.
- NICU support groups
- For the car seats brochures, share with physiatrists, in therapy offices, or with car seat safety check people

- Other

- National
 - The Association of Maternal & Child Health Programs (AMCHP) Conference was held January 24-27, 2015. Tammie and Devaiah attended from CSHS. A broader picture with system changes was a big focus. There also were a lot of things offered under care coordination with the best care coordination occurring in a medical home. There were sessions on redesigning the block grant and outcome measures. Moe, from the Family Advisory Council, also attended the AMCHP conference and attended sessions on family engagement. Different strategies were addressed. The focus has broadened to address MCH in addition to CSHCN (e.g., groups for breastfeeding moms, safety information to families, etc.). Moe also conducted a hill visit with congressional staffers.
- Department of Human Services (DHS)
 - Medicaid Management Information System (MMIS Enterprise) - CSHS staff is working with DHS on this claims payment system project, which is expected to go live June 2, 2015. CSHS staff have been busy testing and training on the new system and are hoping that the transition will go smoothly.

	<ul style="list-style-type: none"> ▪ There are changes in leadership within the Medical Services Division. The current director, Julie Schwab, has resigned. There is no news on any replacement at this time.
MCH Block Grant	<p>Work efforts with the MCH Block Grant have focused on the Title V needs assessment and prioritization process based on new guidance from the federal level. The handout showing national priorities and the MCH population domains was reviewed. Medical home and transition are in the CSHCN domain. Adequate insurance is a cross-cutting issue. A MCH survey will be disseminated to gather public input. This electronic survey will be quick and simple. FAC members were encouraged to distribute it to other families.</p>
Family Advisory Council Project-Data Story Profile	<p>An update was given on the FAC family story project. Council member Joe shared the story and pictures of his family's process through the cleft clinics with his daughter Stella. Advice was asked on how to best move this project forward with the following suggestions:</p> <ul style="list-style-type: none"> • Could get the word out with family support entities and parent to parent. • Website and Facebook would be good place to share these stories. • This would be good to print out and bring to families in clinics. Family stories from those that have attended clinics and have been through the process would be helpful to those that are more newly diagnosed. These stories could be printed and in the waiting area at clinics. • Yearly staff training or conferences. • Could include in CSHS clinic directory. • Send to the legislators. • Could send family stories out to county workers in a newsletter. • Cleft family stories could be put in with gift boxes that are sent out. • Cardiac family stories could be handed out with pink sheets at cardiac visits. <p>FAC members indicated that writing a story helps the family as well as others. It's important that other people know what families go through and how they move forward from a crisis to a better place in the grief process (where they are now). Council member Sarah added that family stories are good for an impact but some families may want permission from their child to share the story. Families may want to represent joys rather than challenges.</p>
Reimbursement Forms/Adjourn	<p>After members submitted reimbursement forms, the meeting was adjourned.</p> <p>The next Family Advisory Council meeting is scheduled for Saturday, May 2, 2015 from 1:30 p.m. to 4:30 p.m.</p>

CSHS Family Advisory Council Recommendation Summary



Meeting Date	Advice	Action Taken
February 2015	<ul style="list-style-type: none"> • Invite FAC representatives to the Medical Advisory Council meeting on May 2, 2015 from 8:30-12:00 noon. • Update the CSHS membership list. • Implement the following suggestions on how better to inform families regarding changes with maternal child health block grant: <ul style="list-style-type: none"> ○ Staff could follow-up with Donene about hosting a Family Voices topical call. ○ Staff could present at the family leadership institute that will be held in June. Moe is in charge of the agenda. ○ Staff could share information at the Pathfinder conference. If another “talking circle” is held, it would be a good opportunity to connect with Native American parents. • Consider the following suggestions regarding the ASD database: <ul style="list-style-type: none"> ○ Share education materials with the council before printing. ○ Inform and involve families as the database is developed. ○ Collaborate with DHS on diagnostic services that will support ASD database reporting. ○ Connect with other groups (e.g., Tribal Social Services, providers, agencies, larger associations/organizations, NDCPD, and early intervention staff). ○ Get employment information from adult individuals with autism. ○ Anticipate how “teams” with multiple mandatory reporters should report into the database. • With new CSHS contract approach, consider parents supporting parents and system navigation as a priority. 	<ul style="list-style-type: none"> • Moe, Sarah, and Lori were invited to the May 2015 Medical Advisory Council meeting. • The membership list was updated. • A Family Voices topical call was conducted by Tammy Lelm and Kim Mertz on 4/14/15. Devaiah presented at the April 2015 Pathfinder conference. • Draft brochures are scheduled for review at the 5/2/15 FAC meeting. Input from families (Pathfinder and Family Voices staff) has been solicited as brochures were being developed. • No action to date.

	<ul style="list-style-type: none"> • Consider dissemination of new CSHS publications via the following: <ul style="list-style-type: none"> ○ Possibly give to the CSHS County Social Services workers to disperse to families. ○ Share with Pathfinder, Family Voices, and other family support organizations. ○ Ronald McDonald Care Mobile, Bridging the Dental Gap, or to those that are doing sealants in schools for the dental resource booklet. ○ School nurses would be a good one to get information out to those that need it. ○ NICU support groups ○ For the car seats brochures, share with physiatrists, in therapy offices, or with car seat safety check people • Consider dissemination recommendations for the FAC family story project: <ul style="list-style-type: none"> ○ Could get the word out with family support entities and parent to parent. ○ Website and Facebook would be good place to share these stories. ○ This would be good to print out and bring to families in clinics. Family stories from those that have attended clinics and have been through the process would be helpful to those that are more newly diagnosed. These stories could be printed and in the waiting area at clinics. ○ Yearly staff training or conferences. ○ Could include in CSHS clinic directory. ○ Send to the legislators. ○ Could send family stories out to county workers in a newsletter. ○ Cleft family stories could be put in with gift boxes that are sent 	<ul style="list-style-type: none"> • Meetings with Injury Prevention and Control staff have been held to develop a dissemination plan for car seat brochures. • FAC family story is on the CSHS website and is being shared with families at clinics and in cleft gift boxes.
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	<p>out.</p> <ul style="list-style-type: none">○ Cardiac family stories could be handed out with pink sheets at cardiac visits.	
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