Children's Special Health Services (CSHS)
Family Advisory Meeting
Saturday, February 20, 2016

NORTH DAKOTA DEPARTMENT of HEALTH
Children's Special Health Services

Attendance:	
Family Advisory Council members	Lisa Beckman, Garrett Schultz, Clifford Klimpel, Evelyn Klimpel, Tara Hope, Joseph Liccinni, Moe Schroeder and Sarah Carlson
CSHS Division staff	Tammy Lelm, Tina Feigitsch, Tammie Johnson, Kim Hruby, Kodi Pinks, Devaiah Muccatira, and Vanessa Peach
Welcome/Introductions/ Announcements	Kim gave a warm welcome and recognized Tara as a new Family Advisory Council member. Participants introduced themselves and provided brief family/staff updates. Kim routed the membership list and had council members update their contact information.
Follow-up from Meeting	November 2015 minutes were accepted as written. Kim reviewed the recommendations from the Family Advisory Council's November meeting with subsequent discussion on the following: • CSHS staff apologized that FAC members were not invited the recent polycom trainings held for county staff. However, they will be made aware of any other future training opportunities. • The Autism Database Administrator has continued to explore the release of a family-oriented news release.
State Updates	County Social Service Finance Working Group • The County Social Service Finance Working Group is a subcommittee that was formed to look at how to make things work if the administration of county programs is taken over by the state. The group is working on/looking at a funding formula that will then be used to work on the budget for this process. There are concerns for potential cuts of general funds. Our CSHS county staff is on the social service side of things and they will have to start being very conservative and watch what programs are added. There is also a possibility having things divided by districts instead of counties. These meetings are set to continue, and minutes are available online if anyone is interested in following. New scoring tool for the Children's Medically Fragile Waiver • Overview of the current waiver was given. Surprisingly, current families on the Medically Fragile Waiver have trialed the new tool and were found to have very low scores. o Families are currently able to share their family story at the end of the application for the Medically Fragile Waiver, which will award them additional points. However, many are not doing this. • A member who had previously completed this application suggested that the families fill out the first copy, and

provide a second copy to be filled out by their physician. At a longer appointment, they can go over the answers together. It was also suggested that families fill out the tool with their child's "worst days" in mind.

- The committee is going back to the drawing board to look at the tool again. Members were asked to look at the tool, score their children, and pay close attention to the scoring. Any comments or concerns that could be brought forward to the committee could then be shared.
- Questions from the tool so far included:
  - Do you evaluate your child based on supports that are already in place?
  - Should PT & OT really be considered medical professionals?
  - Why do some areas have more samples than others? Suggest adding more samples.
- Protection and Advocacy are working with Medicaid to make the scoring fair. There will be opportunities for the public to comment on the tool and Tammy has the information if anyone would like to do so.

DoH Budget

- Tax revenue has been affected from the drop in oil, resulting in an approximately 4.05% reduction in general funds. For CSHS federal funds are matched with the general funds. The health department came up with a plan to bring forward to the governor in which each section came up with a portion. Some budgetary highlights within the Department of Health and Department of Human Services included:
  - There will be a discontinuation of a local vaccine program that was being administered to children who are already covered by health coverage, since these children would still be able to get the vaccines.
  - The Community Health Section met and CSHS fortunately does not need to absorb any of the cut at this state of the game.
  - All departments however will need to look at operating expenses and there will be no travel out of state when using general funds.
  - Autism Services within the Department of Human Services is a large area where cuts will be made which will affect Kodi in our office.
  - Both the judicial and legislative branches are going to be doing the cuts as well even though they do not necessarily need to.
  - The child care inclusionists who go in to child care facilities and work with child care professionals working with children with special needs were given extra funding during the last legislative session. That extra funding will now be going away.
- These cuts could potentially be continuing into the next biennium.
- The contract with Grand Forks Public Health has already ended.
- Things that are already in place aren't necessarily being taken away but there will not be additional items provided. The possibility of a family liaison is still being looked at, but is probably not affordable right now.
- Some providers are also making the decision not to accept ND Medicaid. This impacts Children's Special Health Services because we use the Medicaid system to pay our claims.

MCH Block Grant-technical assistance request and next steps with work plans

- Our two division focuses on the MCH Block Grant are medical home and transition. Medical home is currently made of 5 components, which were reviewed.
- The state can apply for technical assistance, but is unsure of where to start asking for help. Members were asked to review our goals and to voice their ideas. One of the goals was to initiate a medical home coalition.
    - It was requested that at least 30% of the coalition be family members.
        - CSHS voiced uncertainty if we would be able to afford that, but it will definitely be takin into consideration and we will do what we can.
    - One member shared that it is a huge feat to coordinate with families, providers, etc. as a primary focus, so start at a residential level like nursing homes, group homes, or facilities like Anne Carlsen.
- We can change strategies yet this year, but once we do then they are more set in stone and must be carried out and we will have to find a way to measure these areas. We need ideas from our FAC on how to move forward:
    - What is working in your lives, and what isn't working?
    - What would your dream medical home look like and how could we achieve this?
- Currently Minot, Fargo, and now Bismarck do have models for medical home in which they are following.
    - Dr. Carver in Minot follows the model initiated by the ND Integrated Services (NDIS) grant a few years ago. This particular model can be found on page 5 of the booklet that Moe handed out, entitled "Partnering with your Doctor: The Medical Home Approach." However, Dr. Carver has the ability to be more flexible in his practice and is able to assist CSHS in many areas.
    - In Bismarck CHI St. Alexius and Mid Dakota are beginning to implement medical home. Dr. DaSilva at Sanford Bismarck has also expressed interest in the medical home model.
- With the Affordable Care Act providing reimbursement for medical home, we were hoping that this would push more to want to get involved with practicing medical home.
- Care coordination is a struggle here in ND and it is something that our staff is regularly working on.
- One member asked how a family receives care coordination through the county worker for CSHS.
    - When a person applies for the Treatment Program they meet with the county worker to complete the care coordination plan and all other needed paperwork.
- We would really like to know what is happening across the state with medical home. Members were urged to go to their home towns and ask their physicians if they are using a medical home model in their facilities, and if so, bring this information back to the Family Advisory Council.
    - Members were encouraged to keep an open mind and that there will probably not be just one model.
- Members shared their current thoughts on how medical home is going in our state so far:
    - Providers in ND are overworked and that they do not feel like they have the time to take part in using the medical home model.
    - One ND model made it feel like it was just one more person that the parent needed to talk to, because there is no communication within the health system, the parents are still responsible for managing

	everything. o One member shared that she knows several people who participate in a medical home and a huge issue is that their care plans are not being updated at their visits so they are having to either make an additional appointment to get it updated or are having to call in and have it taken care of. • The council asked how other states have implemented medical home. CSHS staff responded: o Some have taken it to the legislature. o Others utilize a certification process that states/providers have to go through. o Some states have a great working relationship between teaching hospitals and universities, which helps in their medical home models. • Discussion was then brought over to the topic of transition. Many of the parents present voiced how they did not do the best of job with their own children and transition. Some shared that they feel it has a lot to do with the individual child and how some are ready at a younger age to start taking care of things on their own. • CSHS sends out transition packets regularly to families. • Some families are hesitant to let their children transition and start doing things on their own, but people should start doing this at a younger age to get their children ready. o One member shared that she has spoken to some families who have 17 year olds and they have concerns about what guardianship is. • It was also mentioned that it has a lot to do with the provider, and when they start fostering the switch to a provider that treats adults. The council agreed that youth seem more likely to listen to this guidance from their provider rather than the parent. • Clifford was asked to share his experience with transition and he said that he starting making his own appointments when he was 17 or 18 and that sometimes he would go alone and sometimes he would have his mom go along. He did mention that his doctor saw both children and adults so he did not need to find a new physician. However, his mother also shared how there was no connection between his doctors in Gillette and those in Minot so they would have to do a lot of the communicating so she did help with that.
Upcoming Conferences	Kim listed the upcoming conferences which follow below: • Pathfinder Parent Involvement Conference-March 3-5, 2016 at the Ramada Plaza Fargo Hotel & Conference Center o Jennifer shared information about the conference and said there are still a few parent stipends available if anyone is interested in attending; website: psnd.co/conference/ . If anyone wants any more information she will send out the information. • Mind Matters -March 29-30 Fargo Holiday Inn o One speaker will speak on school reentry. Minot State University is working on implementing a "return to learn" campaign. • State Development Disabilities Council Health Conference-May 13, 2016 at the Holiday Inn in Fargo o This is a very interactive conference with sessions still being finalized.

	• Dakota Conference on Rural and Public Health-May 16-18, 2016 at the Alerus Center in Grand Forks
	• Newborn Screening/SCID conference-May 20, 2016 in Bismarck
	  o This is a free conference offering CEU's for certain disciplines.
	• Family Voices Leadership Institute- June 10-12 in Edgely, ND
	• ND Conference on injury Prevention and Control (IPC)-August 10-11, 2016 at the Radisson Hotel in Bismarck
	  o Registration is open, and you can register on the DoH website under the IPC page.
	• ND Autism Spectrum Disorder Conference-October 26-28, 2016 at the Grand International Hotel in Minot

Change in Family Advisory Council Meeting Dates/Medical Advisory Meeting Volunteers	• There was discussion about having 3 meetings per year instead of the 4 that we are currently doing since the August meeting is most often cancelled. Everyone agreed on moving ahead with 3 meeting dates and the dates were agreed upon. The dates for the remainder of 2016 and for 2017 are :
	  o April 30, 2016 1:30 pm – 4:30 pm
	  o September 17, 2016 9:00 am – 12:00 pm
	  o January 21, 2017 9:00 am – 12:00 pm
	  o May 6, 2017 1:30 pm – 4:30 pm
	  o September 16, 2017 9:00 am – 12:00 pm
	• Members were asked if they would like to volunteer to partake in the Medical Advisory Meeting on April 30th and Sarah Carlson, Clifford Klimpel, and Moe Schroeder volunteered to attend.

Care Coordination Training-Moe Schroeder	• Moe Schroeder works for Family Voices of North Dakota (FVND), and gave a brief presentation on their Care Coordination Training taking place in various locations across the state. FVND had applied for a "train the trainer" grant, in which the parent is the care coordinator.
	• Families who participate in the training receive a medical home book, a participant book, and a journal in which they do journaling throughout the training. There is also a pre and posttest that is administered.
	• The purpose is for the families to have all of their care plan and information in one document that is signed so they should not have to retell all of their information at each visit.
	• The trainings involve a lot of interaction, discussion on transition, and are a great way to form connections with other families among many other things. The families are offered a stipend, reimbursement of travel, and a meal is provided.
	  o There was a training that took place in Fargo where 6 families attended.
	  o The next training will be either the end of April or beginning of May and will be held in either Jamestown or Bismarck. Moe will provide more detailed information as it unfolds.

Family Engagement Activity	• All that attended the meeting partook in a Family Engagement Activity where each person wrote down two fun facts about themselves, two wishes for 2016, and two ways they wanted to get more involved with Family Advisory or CSHS. After all were finished we went around and tried to guess who wrote each and if we guessed correctly and

	if we couldn't guess it than the person who wrote it shared that it was them. These were all compiled into a list and will be distributed at the April 30th, 2016 meeting.
Reimbursement Forms/Adjourn	After members submitted reimbursement forms, the meeting was adjourned. The next Family Advisory Council meeting is scheduled for Saturday, April 30th from 1:30 p.m. to 4:30 p.m.

CSHS Family Advisory Council Recommendation/Review Summary

Meeting Date	Advice	Action Taken
February 20, 2016	• Update membership contact list.	Tara's information was updated accordingly.
	• Add more samples to the "Medically Fragile" tool.	This committee has not met again to discuss the tool.
	• When organizing the Medical Home Coalition, ensure that 30% of the seats are held by family members.	Efforts to initiate a coalition are still in the planning stages, and all suggestions are being considered.
	• Since medical home is difficult, begin at a residential level such as nursing homes, group homes, or facilities like Anne Carlsen.	This has been noted and will be taken into consideration when implementation is in place.