Children's Special Health Services (CSHS)
Family Advisory Meeting
Saturday, November 14, 2015

NORTH DAKOTA DEPARTMENT of HEALTH
Children's Special Health Services

Attendance:	
Family Advisory Council members	Lisa Beckman, Garrett Schultz, Lori Hanson, Clifford Klimpel, Evelyn Klimpel, and Sarah Carlson
CSHS Division staff	Tammy Lelm, Tina Feigitsch, Tammie Johnson, Kim Hruby, Devaiah Muccatira, and Vanessa Peach

Welcome/Introductions/ Announcements	Tammy gave a warm welcome and recognized Garrett and Clifford as new Family Advisory Council members. Participants introduced themselves and provided brief family/staff updates. Tammy routed the membership list and had council members update their contact information.
Follow-up from Meeting	May 2015 minutes were accepted as written. Tammy reviewed the recommendations from the Family Advisory Council's May meeting with subsequent discussion on the following: • Kim and Tammie gave descriptions of physician needs/updates at the clinics they manage. • The family consultant position within CSHS was discussed. If implemented, it would not be initiated until July 1, 2016. • Kim gave a brief review from the MCH Block Grant review. • Kim and Tammie shared information about the polycom training that was held for CSHS county social service staff. Tammy let the members know that CSHS staff provides technical assistance to local staff on a variety of CSHS programs. Sarah indicated she feels that she is constantly training and spoke from a parent perspective about concerns/issues that she has, including families not having the information that they need. Tammie relayed that CSHS welcomes family members as co-presenters at trainings because that impacts the county workers more than just hearing from state CSHS staff. Sarah said she would be willing to participate in upcoming polycom training events.

	• Tammy talked about the Autism Spectrum Disorder Database (ASD. Sarah asked about the reports that will be available to the public with the information from the ASD database. Tammy let the members know that future reports would generally include aggregate data. She also reiterated that the Health Department will maintain confidentiality and keep protected health information private and secure. Kim shared information from the task force meeting about families concerns about reporting. She also shared information from one parent about how the reporting process was painless. Evelyn shared the perspective of college students who have Asperger's. She relayed some students have concerns with people knowing their diagnosis. Sarah voiced concern about people who do not want it to be reported who won't seek medical help for their disorder. Sarah suggested including a parent story on the CSHS autism website page for those families who are having reservations about reporting as a means to lessen their fears. Lori and Garrett spoke about how hearing it from another parent would mean more than just hearing it from clinic staff or other professional staff. Sarah also suggested possibly having a story or testament added to the next printing of the family brochures.

State Updates	Follow-up to SB 2206-County Social Service Finance Working Group
	• Tammy gave an overview/description of the bill and its potential impact on future funding of county social services, which in turn, has a potential impact on the CSHS budget. Staff have provided CSHS county caseload data to the Finance Working Group. Some of the discussion focused on the following:
	  o Information was shared on the Social Work (e.g., CSHS and other programs) and Eligibility (e.g., Medicaid and other Economic Assistance programs) areas within a county social service office.
	  o Lisa shared that she has good connection with their county/local staff.
	  o Updates regarding this issue was recommended at future meetings.
	
	New scoring tool for the Children's Medically Fragile Waiver
	• Tammy gave overview/description of the waiver, which is to fill gaps for families who are not eligible for other waivers but still need help. "Medically fragile" in this context means complex or significant health needs. This waiver is for individuals up to age 18. Kim shared that the screening tool originally had some criteria which focused on adults but she advocated for making it more kid friendly. She also helped with the hearing criteria for the tool. Another meeting is scheduled for Monday, November 16th to finalize the tool. It was recommended that the old and new version of the tool be shared with council members once it's finalized.
	
	Infant Mortality CoIIN – Collaborative Improvement and Innovation Network
	• Devaiah gave an overview of CoIIN and explained his role. Tammy shared CoIIN's main strategies in ND which include: safe sleep (e.g., hospital crib sheet messaging), smoking cessation (e.g., ND Quits program incentives), pre and early term birth (e.g., hospital pledge regarding deliveries before 39 weeks), and social determinants of health.

	• Devaiah shared posters of adverse experiences and health disparities among ND's American Indian population. Evelyn said that showing positive results would probably reach more American Indians than just showing them the stats. She also recommended use of Good Health TV. MCH Block Grant-on-site review and next steps with work plans • Tammy gave overview of MCH block grant and shared ND MCH national priorities with the group. Two of these priorities are specific to CSHS: 1) medical home, and 2) transition from youth to adulthood services. • Kim gave overview of the plan to increase utilization of Medical Home. Advisory council members talked about their experiences. Garrett said that overall he feels that they have had a good experience and that their providers did a good job linking them to who they needed. Sarah said in her dream home there would coordination with in-state and out-of-state care. Both said that working between states is difficult because people don't really communicate. Care coordination is sometimes lacking. Family partnerships were felt to be important. • Tammie talked about the plan to increase the number of children receiving transition support. Clifford shared that coordination between specialists and local physicians could be difficult. He recommended educating youth transitioning into adulthood and providers and to be more accountable with entry into college. Lori shared how she had her children start checking in at the clinic when they went in for visits so they became familiar with the registration process.
Upcoming Conferences	Tammy listed the upcoming conferences which follow below: • State Development Disabilities Council Health Conference-May 13, 2016 at the Holiday Inn in Fargo • Newborn Screening/SCID conference-May 20, 2016 in Bismarck • ND Conference on injury Prevention and Control-August 10-11, 2016 at the Radisson Hotel in Bismarck
Family Advisory Council Member Updates	Sarah shared her experience going through an out-of-state appeal with Medicaid. Her child has had 17 surgeries and requires care from an out-of-state pediatric neurosurgeon, which had been denied. She reiterated how hard parents have to fight to get what their child needs.
Parent Resource for Employment Preparedness in Transition (PREPT)	Guest Presenter Rhonda Weathers gave a presentation on a project she is working on entitled *Parent Resource for Employment Preparedness in Transition* (PREPT). She is planning training workshops in four communities across the state in the spring of 2016. Specific dates were not yet available. Discussion and suggestions after the presentation included the following: • Tim video - employment focus vs. "hugs". • Examples of employers of individuals with developmental disabilities would inspire others. • Share Rhonda's newsletter with CSHS • Living wage and benefits like health insurance are a motivator.

	• NDCPD has a total of five projects on transition. CSHS could promote these programs and include information on them in the division's transition packets. • Share Rhonda's PowerPoint presentation with council members.
Reimbursement Forms/Adjourn	After members submitted reimbursement forms, the meeting was adjourned. The next Family Advisory Council meeting is scheduled for Saturday, February 20th from 9:00 a.m. to 12:00 p.m.

CSHS Family Advisory Council Recommendation/Review Summary

Meeting Date	Advice	Action Taken
November 14, 2015	• Update membership contact list.	Membership contact list was updated prior to the 2/20/2016 meeting.
	• Provide opportunities for families to present their parent perspective at CSHS polycom trainings for county social staff.	Sarah was not asked to present at the December polycom training but staff will check on her future availability as trainings are scheduled.
	• Include parent story/testament on CSHS autism webpage and add to autism database family brochure when it's next printed.	Staff have disseminated ASD database brochures via the clinic directory mailing and informed providers about the ASD reporting requirement via the HAN. Staff are currently working with PIO's on a family-oriented news release and will try to include a family quote. The website has not yet been revised.
	• Provide an update on SB 2206 and the Finance Working Group at the next FAC meeting.	Item was included on the 2/20/16 meeting agenda.
	• Share the final ranking tool for the medically fragile children's waiver.	Item was included on the 2/20/16 meeting agenda.
	• Share positive results with CoIIN activities for the American Indian population in addition to stats on posters that are developed. Consider use of Good Health TV.	Working with staff at Aberdeen Tribal Chairman's Health Board and American Indian Public Health Resource Center at NDSU on facts sheets that include information on resiliency.
	• Provide education for transitioning youth and providers.	No activity to date.
	• Promote more care coordination, especially between in and out-of-state care.	Staff provide care coordination, upon request.

	• Share information from NDCPD transition projects. Consider including it in CSHS transition packets. Share PowerPoint presentation with FAC members.	Transition packets are currently being reviewed for possible updates as part of CSHS library review process. PowerPoint presentation was sent to FAC members.