

## **Children's Special Health Services Family Advisory Council Meeting**

**Saturday, November 16, 2013 - 9:00 p.m. to 12:00 noon CST  
Comfort Suites, 929 Gateway Avenue – Bismarck, ND**

### **Welcome/Introductions/Announcements**

Present from the Family Advisory Council: Carla Peltier, Laura Roberts, Lori Hanson, Jennifer Restemayer, Donene Feist, Lisa Beckman, Cheryl Klee, and Evelyn Klimpel

Present from the Children's Special Health Services Division: Tammy Gallup-Millner, Tammie Johnson, Melissa Evans, Devaiah Muccatira, Kim Hruby (Marissa), and Carrie Tate

Guest Speaker: Tammy King

Absent: Moe Schroeder and Joseph Liccini

- Updates from Family Advisory Council Members – Members relayed that conferences/meetings are coming up this spring.
- Dates for Partners in Policymaking Sessions for 2013-2014 have been set. For more information, call 888-258-7949 or link to: [www.thearcofbismarck.org/Partners](http://www.thearcofbismarck.org/Partners).
- Donene Feist with Family Voices of ND (FVND) relayed that they are continuing with topical calls. She shared a transition wheel developed by Family Voices of Colorado. FVND will be purchasing 1,500 of them at a cost is \$3.50 each. Donene will send some to CSHS when they arrive. FVND plans to develop a ND version of the wheel.

### **Follow-up from May 2013 Meeting**

- The membership list was reviewed with no needed updates at this point in time. Members were asked to contact Tammy with any changes, if they arise.
- May 2013 Family Advisory Council minutes were approved as written. Council members commented that legislative update was very thorough and that they had found it helpful. Council members were asked regarding their preference for detailed vs. condensed minutes and indicated detailed minutes were preferred.
- The Recommendation/Review/ Summary was reviewed with council members.
  - The Family Handbook, which was recently revised, is currently being printed. It will soon be available for distribution. The new version is up on the CSHS website.
  - Carla agreed to another term on the Family Advisory Committee.
  - Contact information for Lori was confirmed via an e-mail "test".
  - The Family Advisory Council membership list was revised to include recommended content (e.g., 800 number, CSHS e-mail address, etc.).
  - Council member recommendations regarding CSHS webpage revisions were reviewed and the following changes made: 1) a buffalo graphic was added to

identify state links on the CSHCN Service System pages, 2) family support options were included, and 3) a disclaimer was added. CSHS staff were unable to add a search button and opted not to break out mental and physical components. Staff have two system pages left to complete: community based systems and access to medical home.

## Updates

- National Update –
  - MCH Block Grant Follow-up:
    - Family Participation Ranking for the MCH Block Grant – Ranking of family participation in program and policy activities in the state CSHCN program for FFY 2013 was 17 out of 18 based on combined input of CSHS staff and the Family Advisory Council membership. The following scale was used by CSHS staff:
      - 0-25% = not met, 26-55% = partially met, 56-84% = mostly met, and 85% or more = completely met.
    - Highlights were shared for State Performance Measure #1 that addresses partnerships with families and American Indians. The greatest increases over the period 2010-2013 follow:
      - Family representation on committees, task forces, coalitions, etc. increased from 51% to 65%
      - Family collaboration around programmatic services increased from 55% to 65%
      - American Indian collaboration around programmatic services increased from 48% to 63%
      - American Indian collaboration around community mobilization increased from 31% to 50%
      - For the period 2010-2011, family collaboration around advocacy and public policy increased from 50% to 58% and American Indian collaboration around data increased from 38% to 46%.
    - Family Advisory Council members recommended that staff continue to review their suggestion when working on the annual MCH Block Grant plan. Members asked if transition packets were available online. Currently packets have to be requested and mailed. Tammy relayed that formal feedback from the block grant review has not been received. A council member commented that they would give ND a glowing review compared to other states.
  - MCH Transformation – Significant changes are anticipated with the MCH Block Grant. Some of the discussion points follow:
    - The block grant may be narrowed down to core areas instead of being so broad.
    - There will likely be changes to the grant guidance and performance measures.
    - There will likely not be any changes to the federal law so vision, mission and target populations should stay the same.

- Other related grants will be aligned (e.g., SSDI grant).
    - There will likely be separate accounting for state and federal funds.
  - Other federal updates follow:
    - A federal survey was done to assess service reimbursement similar to insurance. In CSHS, we are gap-filling what insurance does not pay. We do not duplicate. Our focus is on underinsurance coverage.
    - An update was provided on funding. A Notice of Grant Award (NGA) was received for the MCH Block grant but not yet for the SSDI grant.
  - Moe was appointed to Family Youth Advisory for AMCHP.
- Department of Health MCH Update
  - Within the Health Department, CSHS has moved from the Special Populations Section to the Community Health Section (CHS). Tammy has joined the leadership team for the section. Benefits anticipated with being part of a larger section include relief of some workload burden for staff and better programmatic integration opportunities.
  - Newborn Screening is celebrating its 50<sup>th</sup> anniversary. A display is on loan to hospitals to increase awareness about the importance of newborn screening in ND. Donene relayed she could send out an alert if any family stories are needed regarding newborn screening.
  - A Pediatric Dental Day was held at Standing Rock on October 11-12, 2013. It provided needed dental care for the community. Dental providers came from all over and were able to help lots of children. Last year they held a similar day in Spirit Lake. The council discussed services through IHS, which generally lacks adequate funding and staff resources. Council members relayed another myth around the Fort Berthold area is that all American Indians have oil money. In reality, the number is quite low. Members were interested in finding out whether another Dental Day is planned on any of the other reservations.
  - *A Connection Directory for Families and Agencies* has recently been updated and is available on the following website:  
<http://www.ndhealth.gov/familyhealth/publications/ConnectionDirectory.pdf>.

### **Affordable Care Act**

The following initiatives were discussed with Family Advisory Council members as part of the Affordable Care Act:

- Overview of Medicaid Expansion and Marketplace – Power Point Presentation and other handouts were provided. Starting in January 2014, North Dakota will be expanding access to cover more individuals
  - Enrollment is starting November 2013.
  - Some individuals turned down in the past may now qualify
  - There will still be some people that are required to pay copays
  - For Medicaid expansion, coverage will be outsourced like the state does with Healthy Steps using Blue Cross Blue Shield
  - Online applications are encouraged
  - Should American Indians still sign up? This would bring additional dollars into IHS, so hopefully they can provide more services and better serve the American Indian community members.

- An AMCHP resource was shared that was an overview of coverage and essential benefits for MCH populations under the Affordable Care Act.
- There will continue to be some remaining uninsured such as undocumented populations who will not have access to coverage.
- Tammie Johnson relayed that in CSHS, staff are working on getting information out to those that are uninsured. Information sheets regarding the Health Insurance Marketplace and have been provided in addition to the Health Care Coverage brochures that are routinely sent out.
  - Members suggested that Minot State University's phone number be added to the information sheet since they are currently the navigator hub for the Health Insurance Marketplace.
  - Also it was suggested to add in the Great Plains Tribal Chairman's Health Board information, since they also are one of the navigator grantees.
  - Members relayed that gaps could get bigger with some of the marketplace plans and families may have to pay more out-of-pocket.
  - Donene relayed she is now on Senator Heitkamp's health advisory committee.
- Donene Feist provided an update on Navigator Grant Activities.
  - Family Voices employees are navigators, which adds another level of complexity in an already complex system. They've received some negative feedback for becoming navigators from those that do not agree with the Affordable Care Act (ACA).
  - BCBS, Sanford and Medica provide coverage in ND
  - There are four levels of health insurance plans available: Bronze, Silver, Gold, and Platinum (metallic plans)
  - All plans have essential benefits but none of the policies include habilitative language. This is being reviewed at the federal level and may need to be looked at within the Insurance Department. Therapy visits are limited to 30.
  - Families can have both Marketplace insurance and Medicaid but they can't get subsidies if they do so
  - Navigator training is 20 hours and there are questions coming in to the navigators that the state navigators cannot answer until federal clarification is given
  - An exemption process for families with children with special health care needs may be needed.
  - If you enroll by December 15, 2013 you should be able to get coverage as of January 1, 2014.
  - Applications are now coming through online on the Marketplace website, (healthcare.gov) however, hardcopy applications are also available.
  - An eligibility tool is available through Kaiser.
  - For income, net (adjusted gross) income is used on the application. If the premium is 9.5% or higher of a person's net (adjusted gross) income for employer coverage, then they have the option to go through the marketplace – but they would have to show proof that the premium is 9.5% or higher than their net income.
  - Subsidies go to insurance companies to reduce premiums, not individuals
  - For income, line 21 on the 1040a is used to show income from last year's tax return

- Navigators are there to help with this application process. Other entities are helping as well (e.g., Community Health Centers, hospitals, etc.).
- Minot State University (MSU) is one entity and Great Plains Tribal Chairman's Health Board (GPTCHB) is the other entity providing navigators in North Dakota.
- Currently there are 17 people through Minot State University that are navigators in the state.
- Some families may experience challenges with Grandfather vs. non-Grandfathered plans

### **Transitions - Healthy and Ready to Work**

- Tammie Johnson welcomed guest speaker, Tammy King, a counselor with the Division of Vocational Rehabilitation.
  - A Power Point Presentation was provided on the ND Division of Vocational Rehabilitation (DVR) Transition Services
  - DVR helps people with employment goals available through state and federal funding. There is an "order of selection" waiting list currently.
  - Students do not need an Individual Education Plan (IEP) to qualify for services. Usually the school will refer for services; smaller schools usually tend to refer more than larger schools.
  - Parents have to advocate for their kids to be tested and it is the responsibility of the high school to do the testing.
  - There are eight offices in the state of North Dakota, one in each human service center region.
  - Some schools have student led IEP meetings that are very helpful.
  - Counselors look for any limitations to help with eligibility. There are many barriers when transitioning, but some individuals are so used to accommodating their limitations that they do not fully realize these limitations.
  - Healthcare transition is a very important part for the overall transition.
  - Other website resources:
    - DVR website: <http://www.nd.gov/dhs/dvr/individual/student.html>
    - ND Youth Forward website: <http://ndyouthforward.com/>
    - Launch My Life website: <http://launchmylifend.com/>
- An update on Leading Your Health Transition! was provided by CSHS staff member Tammie Johnson.
  - The presentation CSHS developed was provided in a packet of information to council members. It can be used by others. Tammie has the electronic version and is willing to present if requested.
  - Additional information was also provided (e.g., communicating with the doctor, Public Health resources, other helpful tools etc.). Transition packets are available at the CSHS office.
  - Council members suggested that a topical call could be done on this topic.

### **Family Advisory Council Project-Data Story Profile--Moe Schroeder**

This agenda item was put on hold and will be addressed at another time.

Reimbursement Forms were submitted and the meeting adjourned.

**The next meeting is scheduled for Saturday, February 8, 2014 from 9:00 to 12:00.**

Note: This is the second Saturday in February rather than the third Saturday.