ASD Taskforce Meeting March 6, 2017

Taskforce members Present: Melanie Phillips, Gerry Teevens, Connie Lillejord, Teresa Larson, Vicki Peterson, Kodi Pinks

Taskforce member present -via Polycom: Nancy Crotty, Tom Gaffaney, Maryann Jaeger, Dr. Engler, Carol Johnson

Guests (present & via Polycom): Kaitlin Kurtz, Lorena Poppe, Rachel Hafner, Jo Carpicle, Kayla Soleim, Heather Steffl, Paula Hinton, Becca Frieje, Kathy Barchenger

March 6 meeting was called to order:

Review of minutes -September / November

September 26, 2016 and November 14 2016 minutes were presented .Discussion held resulting in revisions being purposed as follows:

September revisions:

Maryann Jaeger's name being added to the taskforce attendance via Polycom.

 ASD Taskforce members recommending new members: discussion held to replace Dr Dobinksy, switch Department of Health's representative from Kim Hruby for Kodi Pinks, and to have Senator Heckaman draft a legislative bill to add additional members to the taskforce (Tribal member, self-advocate and Behavioral Health).

Member Connie Lillejord, Made the motion to recommend the replacement of taskforce member Dr. Dobrinksy:

Second to motion: Member Vicki Peterson **Vote**: 9 yay/ 0 nay. Motion passed.

 Member Connie Lillejord; Made the motion to have Kodi Pinks become the new task force member, replacing Kim Hruby as the Department of Health representative.

Second to the motion: Member Vicki Peterson Vote: 9 yay/ 0 nays. Motion passed.

Member Vicki Peterson: Made the motion for Senator Heckaman to draft the Legislative bill.

Second to the motion: Member Connie Lillejord Vote: 9 yay/ 0 nays. Motion Passed

November revisions:

Carol Johnson's name being added to the November minutes.

Approval of September and November minutes: discussion held to approve the meeting minutes for September with additions determined at March meeting and November minutes.

Member Teresa Larson: Made the motion to approve revised September minutes and November minutes.

Second to the motion: Member Gerry Teevens Vote: 10 yay/ 0 nays. Motion Passed

New Business:

Autism Services: update presented by Katherine Barchenger –State Autism Coordinator (handout given to members)

- Currently on the Waiver there are 43 active participants-8 of these children are "aged out" with one of the 8 turning 10 at the end of March.
- There are 3 pending completion of Vineland II
- 46 total
 - O What are we doing?
 - Sending out letters to families telling them there is a slot available and to contact our office to talk further about it.
 - 1 family decided to remain on voucher program
 - 1 family qualified for DD waiver
 - 1 family stated they did not see a need for the waiver anymore
 - 1 family is "thinking about it"
 - 1 family is working on gathering packet(we only have videos)
 - 1 family is looking for completed evaluation
 - Multiple families have no responded to letters
- Working on getting the 12 lined up for amendment increase
- Submitted evidence based report and have not heard anything back from CMS

The amendment for removal of services and move age limits to 3 through 9 year is still pending with CMS. There was a conversation with CMS on 2-22-2017 and it was stated that until the state plan was approved we should not submit the amendment. CMS representative has stated they would reach out to the CMS team for an update, haven't heard anything back.

- There are currently 47 children on the voucher
- 3 are pending-waiting on diagnosis or income verification

Reminder: Welcome to join call-second Tuesday of the month, 10:00-12:00 call 701-328-7950 code 118775

Discussion held as to how to possibly help move approval of state plan along. Discussion held as to possible need of letter from Taskforce to Congressional delegates in regards to the need of the state plan being approved.

Member Teresa Larson: Made the motion for a letter to be written to Congressional delegates.

Second to the motion: Member Vicki Peterson Vote: 10 yay/ 0 nay. Motion passed

Member Connie Lillejord: Made the motion for Teresa Larson to reach out to Congressional delegates.

Second to the motion: Member Gerry Teevens Vote: 10 yay/ 0 nays. Motion passed

Department of Health: update presented by Kodi Pinks- Dept. of Health

Kodi stated that there have been 325 cases of ASD have been reported into the database.

- Kodi contacted 14 boards and associations for the advisory group. 9 people were appointed. The
 advisory group is going to look at issues with mandated reporting, how to reach out to providers
 more effectively.
 - o The board will meeting March 25, 2017. Kodi stated that she also asked family groups.
- The 4 page report form has been revised down to 2 pages. (1 page for diagnosis information and 1 page for family information.)
 - Kodi is also looking at options for entering the reported information into the database
 - Re-drafted the report form to be 2 pages, instead of four pages. This is the draft that was handed out at the meeting.
 - Another report from draft would collect provider information on one page. The
 other page could be given to the families to fill out and send in. The perk of this
 option is that it could find out which providers aren't submitting to the NDDoH.
 - The last option may or may not be possible. (I have to talk to the NDDoH staff that work with MAVEN). This option has providers submitting basic contact information into MAVEN. If the person hasn't been reported, the providers would be sent a link to finish filling out the rest of the report form.

DPI updates: presented by Member Gerry Teevens -

- There are 1,174 students on IEPs that have an autism diagnosis
- March 23-24 2017 Early Childhood Conference in Mandan, Baymont Inn & Suites
- April 4 2017 "Advanced" PTR training- Bismarck Career Academy
- April 5-6 2017 "New Participant" PTR training- Bismarck Career Academy
- August 9-10 2017 Special Education Summer Institute- Bismarck Ramada Hotel
- October 3-4 2017 Northern Plains Law Conference on Students with Disabilities- Billings
 MT
- October 11-13 2017 ND Fall Educators Conference-Bismarck Event Center
- November 8-9 2017 Secondary Transition Interagency Conference-Bismarck Ramkota Hotel
- ESSA Every student Succeeds Act: Law replaces the No Child Left behind Law. The ND ESSA Plan has been written with immense stakeholder input. Special Education has been

at the table. State and local special education representatives have been working through participation in the planning committees to assure the best interest of students with disabilities is considered throughout. The law requires long term goals for progress for students with disabilities as well as appropriate accommodations for inclusion in the state assessments. Special Education is working with the ESSA Planning Team to assure the ESSA Plan includes approaches to support schools districts with continuous improvement efforts, in ways that aligned with the infrastructure approaches described in the special education State Systemic Improvement Plan (SSIP).

- ESSA plan out for public comment Feb. 15, 2017
- o Prevised template coming March 13, 2107
- ? Create Focus Groups
- o Passa Training Plan: East May 4 West May 8
- o Brochures and webinars will be created
- o Submit plan April 1, 2017

Developmental Disabilities- presented by Tina Bay- Director of Developmental Disabilities

- The year for eligibility starts new every April 1 and goes through March 31. At the beginning of the waiver year, there are about 800-1000 slots available.
- There are approximately 60 slots left. Once those slots are filled, there are 190 reserved slots that can be used for needing infant development, extended services and emergency situations.
- There are roughly 800 on the DD waiver with an autism diagnosis.

ND ASD Advocacy Coalition: update given by Member Teresa Larson

ND ASD Advocacy coalition is meeting Thursday March 9th 2017

Anne Carlsen: update given by Member Connie Lillejord-

- The Ziggurat training was canceled. They are trying to reschedule it for possibly April or May.
- Anne Carlsen is trying to get out west for a diagnostic clinic. They are bringing more people into the diagnostic clinic to help.
- 3 months is the average wait for a diagnostic clinic.

UND: update given by Member Carol Johnson

- BCBA is now called the "ABA" program. The paperwork to complete a specialization within the Masters degree in Special Education is just being completed. Currently, students apply for the SPED Masters and complete the courses needed for the BCBA.
- UND is working on an option for students who don't want to obtain a Master's degree to apply for a certificate in this area. Right now, if they are not in the Master's program and want the course work they register as non-degree students.

• UND as an FTE position in ABA and are completing a search.

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Family Voices: update given by Member Vicki Peterson

- Care Giver Café Training-Copyright by Family Voices
 - The project is targeted to caregivers of children and youth with autism spectrum disorders to provide a tool kit for the daily and long term issues of caring for their child. Planning for the future by implementing activities identifying specific needs, providing local and community resources, creating and sustaining a plan for their child into adulthood and planning for unexpected situations and networking with other caregivers.
 - To date there have been 8 trainings/82 parents across the state trained/2 Fargo, 1 Grand Forks, 1 Turtle Mountain, 1 Minot, 1 Bismarck, 1 Jamestown and 1 Standing Rock.
 - This training is for all parents who have children/youth with special health care needs. Vicki has trained specifically for caregivers of children with Autism in a prior Autism Speaks grant.
- During the Care Giver Café training, Vicki learned that caregivers have paid from \$1500 to \$17,000. Parents come and ask for financial help, which there is very little of. In the training, Vicki encourages caregivers to start thinking about guardianship early for those specific reasons.
 Vicki also discusses the rights of a child and refers to law, but it can be difficult to understand.

Legislative Updates:

- SB2241-Database, searchable, update/amend diagnosis-failed
- SB 1012-Lorena Poppe and Trisha Page of Ann Carlsen spoke with Rep. Pollert in regards to the age increase (through the children's 11th birthday). Rep. Pollert stated that it is still moving forward.

Meeting adjourned.

Next Meetings:

- June 5, 2017
- September 11, 2017
- November 20, 2017