

## ASD Taskforce Meeting November 20, 2017

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

**Taskforce member present -via Polycom:** John Watkins, Maryann Jaeger (afternoon), Carol Johnson (afternoon), Nancy Ulrich-Crotty, Senator Joan Heckaman

**Guests** (present & via Polycom): Kathy Barchenger, Kaitlin Kurtz, Erin Bratner, Kim Hruby, Krista Fremming, Maggie Anderson, Susan Gerenz, Lorena Poppe, Sandy Smith, Krisann Miller, Katie Alsted, Paula Hinton, Steven Olson, Summer Van Rooyen, Senator Curt Kreun, Senator Lonnie Laffen

**November 20th meeting was called to order.**

**Review of minutes** – March minutes were reviewed. They were reviewed during this meeting because during the June meeting there wasn't a quorum of taskforce members present.

Tom Gaffaney's name needs to be spelled correctly. Taskforce agreed to move forward with approving these minutes.

Motion to approve the minutes: Gerry Teevens

Second: Teresa Larsen

Vote: 9 yay/ 0 nays: motion passed

**Review of minutes-** September minutes were reviewed. The following needed to be corrected before taskforce would approve the September minutes.

- *Children and Family Special Health Services* needs to be changed to Children's Special Health Services and will transition to Special Health Services on October 1 ,2017

Motion to approve: Teresa Larsen

Second: Vicki Peterson

Vote: 9 yay/ 0 nays: motion passed

Workgroups (formerly called subgroups):

- The workgroups have been condensed from 5 groups to 3:
  - The overall ASD Taskforce Plan: formatting and the flow of information
    - Senator Heckaman, Vicki Peterson, Teresa Larsen and Melanie Phillips
  - Children:
    - Gerry Teevens, Carol Johnson, Connie Lillejord, Kodi Pinks, Thomas Carver, Susan Gerenz, Lorena Poppe and Steve Olson
  - Adults

- Vicki Peterson, Nancy Ulrich Crotty, John Watkins and Teresa Larson
- The expectations of the work groups are as follows:
  - Review state plan for applicable suggestions;
  - Identify potential policy proposals
  - Cover supporting families pieces; cover transition pieces
  - Include fiscal estimates and funding options
  - At least one meeting between each taskforce meeting; materials from meetings distributed at least one week before the next scheduled task force meeting
- The previous workgroups were:
  - Overall plan
  - Children
  - Adults
  - Supporting families
  - Transitions

**Updates:**

**Autism Services: given by Kathy Barchenger**

**Voucher:** The voucher is full at 53 slots.

**Waiver:** working on informing families on the waitlist about the open slots on December 6.

**ABA Services:**

Discussion was held on the development of document to be shared with schools, ABA providers and DDPM. The document was composed by Susan Gerenz of DPI, Amanda Carlson of DD Services and Katherine Barchenger of Medical services. There has been some recent confusion of when Medicaid ABA Services can be used within the school setting.

Taskforce asked questions/ clarification about process within the school for ABA services and were informed services provided within the school must be on a child's IEP and the provider must contract with the school as a related service.

Also shared with the group was the fact sheet for the Medicaid ABA Services. Discussion was held on the section of "what to be expected". Vickie Peterson of Family Voices stated it sounded more like a guarantee but that in fact there are already wait lists due to so few providers. It was suggested to change this section to "explanation of services". The department agreed to review the fact sheet.

**Department of Health: given by Kodi Pinks**

- The revised report form is still a work in progress (going from 4 pages to 2 pages), Kodi is hoping to start using the new form by the start of the new year.
- Survey report form is no longer an option (the surveillance software isn't available).
  - Right now, it is available as a fillable pdf. The report can be submitted electronically.
  - When the Department of Health changes their web base the electronic submission will no longer be a viable option. Electronic submission part would have to be completely rebuilt under the new web base or not have it all. Only the fillable pdf would be left then.
- Surveillance system will have a new opportunity in the future for providers. The providers will have to receive a username and password from DoH-then the providers would be able to log into the surveillance system and report their patients with an ASD diagnosis.
- As of right now, 470 individuals have been reported to the database.
- Funding has been set aside for HIN (Health Information Network) to get individuals with ASD diagnosis from their electronic health records.
  - This would provide more accurate numbers for children and adults with an ASD diagnosis. It wouldn't have the additional information that the report form collects.

**Additional DoH updates presented by Kim Hruby:**

- Applications for the new contract cycle-covering diagnostic clinics
- Grand Forks (Altru) has decided not to continue their Developmental Disabilities clinic that they held in Fort Totten, they felt like the services were duplicative.
- Minot State has expanded their autism diagnostic clinic to Belcourt
- Grand Forks autism clinic is doing well with their foundation funding (they didn't need to request additional funding). They were able to add 1-2 clinics per year to their schedule.

**DPI updates: Provided by Gerry Teevens**

- Prevent Teach Reinforce to 78 teachers who work with students with behavioral challenges.
- Training on Unilateral Placement and Student Notifications
- Training on self-Regulation, Executive Functioning, and Writing Social-Emotional goals in the IEP at the State Autism Conference.
- DPI is working with DHS on an informational paper-ABA in Schools
- Training on an information paper: Transportation as a Related Service in the IEP to Social Service/Tribal/DJS supervisors and case managers.
- DPI and Special Education Office is continuing to provide technical assistance and resources to special education units as they continue their continuous improvement to improve graduation rate of students with emotional disabilities.
  - They have supported the units in trainings for their staff to implement evidence based practices to engage students with behavior challenges, social-communication challenges, mental health needs and emotional disabilities. (This has included self-regulation programs, such as Zones of Regulation and Nurtured Heart).

### **Anne Carlsen: update given by Member Connie Lillejord-**

- Went down to Georgia with a group to the Marcus Autism Center in October. They also went to Emory University.
- The group was able to see research being conducted with eye contact and eye tracking with infants 12 months and younger. (Probably been in the work for the past 5 years)
  - The infants that they chose for eye tracking were siblings of children with autism. The high probability- 20% of siblings with families who already had a child or children with ASD.
  - The siblings are younger and they start at about 2-6 months. They are specifically able to pin point eye movement and where they are looking at on a screen (human face-eyes, mouth or if they are looking at the corner of a room).
    - There is a period of plasticity- if signs of autism are present, they can start working with the child
  - Changes are being seen at 18 months-2 years- they are making progress.
  - They have a charter middle school (7<sup>th</sup>-11<sup>th</sup> grade)-50% of the school is children with autism.
  - Emily Reuben was the host for the week. She has the “SEEKS” model. “Social Emotional Engagement, Knowledge and Skills”
    - Trains teachers in the schools and over video.
    - Universal design for learning-they know it works
  - Marcus Autism Center is having infants and toddlers wear recorders in the pockets of their onesies that records the interactions (audio) for 12 hours/day.
    - It’s recording what’s happening to the kids who are diagnosed with autism and the decline in their engagement with their social environment and at the same time monitoring how the adults and people in the environment decline with them.
      - Trying to reverse the decline with the adults and people when you don’t get the response-you need to put your social responses in those kids who aren’t giving you the response.

### **Senator Joan Heckaman:**

- Attended the Health Services Committee hearing on October 24<sup>th</sup> in Grafton
- There was an article in a newspaper about possibly housing young adults with autism at Grafton
- There is a lot of empty space that can be utilized at Grafton. Who would utilize the space? What would the cost be?

### **Family Voices: Update provided by Vicki Peterson**

- Working to support families- what do you do when there is no program/alternative that will not take a child with extreme behaviors?

- Family Voices is seeing an increase in divorce rates with the families that they are supporting- the financial burden is quite high, the stress of a child with special needs. The families are at a loss of what to do.
- Training on ABLA accounts- collaborative phone calls and in person meetings have taken place.
  - Benefits, how they work. Provided the link for the policies
- Training on alternatives to guardianship
  - The costs of guardianship-the costs can be expensive (emergency and regular guardianship). The prices will vary-dependent on what the attorney charges.

**Teresa Larsen:**

- Protection and Advocacy will be receiving a grant from the SCDD for a project “supported decision making”
- Protection and advocacy has new staff members to fill vacant positions: Matt Kramer- Fargo advocate; Brittany Hanson- Bismarck advocate and Cynthia Goulet-employment attorney.

**University of North Dakota-Update provided by Carol Johnson**

- Starting January there will be a pilot program with the certificate program.
  - The first 8 weeks would be intro methods
  - The second 8 weeks would be the assessment and an elective.
    - Could possibly finish the certificate in one semester

**Motion to adjourn the meeting:** Connie Lillejord

**Second:** Kodi Pinks

**Finalized:** Melanie Phillips

**Meeting adjourned.**

Next Meetings: To be determined

Transcribed on: 12/7/2017