

Autism Spectrum Disorder (ASD) Task Force Meeting Minutes February 4, 2019

Task Force members present in person: Krista Fremming, Teresa Larsen, Vicki Peterson, Kodi Pinks, Gerry Teevens

Task Force members present via polycom/phone: Dawn Hanson, Holly Johnson, Connie Lillejord, Heather Opland

Absent: Dr. Thomas Carver, Jennifer Flores, Senator Joan Heckaman, Mary Jaeger, Carol Johnson, Nancy Ulrich-Crotty, John Watkins, Catherine Yeager

A quorum of Task Force members was present.

Guests (present and via polycom/phone): Katherine Barchenger, Sarah Fuchs, Susan Gerenz, Kaitlin Kurtz, Melanie Phillips, Lorena Poppe, Sandy Smith, Renee Stein, Matthew (student from University of Jamestown)

Meeting was called to order at 1:03 p.m.

Review of minutes- October 2018 meeting minutes were reviewed.

Teresa Larsen made the motion to pass the minutes. Gerry Teevens seconded the motion. 9 yay/0 nay. Motion passed.

2018 ND Autism Conference and Evaluations-Sarah Fuchs, Anne Carlsen Center

The 5th annual ND Autism Conference was held October 24 and 25, 2018 in Grand Forks at the Alerus Center. The conference was shortened to two half day sessions from 2 ½ days scheduled for past conferences.

The conference opened with keynote speaker, Carol Gray.

- Carol is a nationwide consultant who works with children, adolescents and adults with autism.
- Carol is best known for her development of social stories. Carol's presentation was on her social stories and her history.

Following the keynote speaker was the Legislative Panel. The Legislative Panel was new to the conference. The conference committee felt with the upcoming Legislative Session and an increase in needs for services for families and individuals with autism spectrum disorder (ASD), it would help to have a panel discussion. The panel was moderated by Donene Feist of Family Voices. The following topics were discussed:

- Strategies to support and encourage employers to apply individualized supports to maximize the potential of employees with ASD in the workplace.

- Solutions to provide funding in addition to the voucher program to help families with travel expenses incurred while seeking access to care.
- Consideration of a voucher program for adults who have autism, knowing that this target population has and will continue to grow.
- Measures to address significant increases of complex behavioral health issues in schools.
- Strategies to address underfunding in K-12 public education including special education.

Legislators who participated:

- Senator Kyle Davison (R)-District 41
- Senator Curt Kruen (R)-District 42
- Senator Judy Lee (R)-District 13
- Senator Joan Heckaman (D)-District 23
- Representative Shannon Roers Jones (R)-District 46
- Representative Thomas Beadle (R)-District 27
- Representative Robin Weisz (R)-District 14

The legislative panel was well received. The committee would like to see the legislative panel be part of future conferences. It is an opportunity for leaders and constituents to have continued open dialogue about the needs of individuals and families with ASD.

The second day of the conference was break-out sessions. There were three different speakers at each session. The following sessions were presented:

- The ABC's of Applied Behavior Analysis (ABA): Growing Pains of a New Field of Science-presented by Taylor Hill
- Supporting Adults with ASD-presented by Heidi Paulson, Holly Johnson and Tim Odegaard
- "Letting Go" - Moving from Pediatric Care to Adult Care-presented by Vicki Peterson and Melissa Schroeder
- Early Intervention and Autism-presented by Zachary Jones
- Depression, Suicide and ASD-presented by Jennifer Flores
- Peer Mediated Intervention and Instruction (PMII)-using peers to increase positive social interactions for our students with Autism-presented by Laura Gillan
- The Nuts and Bolts of an Autism Classroom-presented by Adie Hobert and Jackie Loepp-Trautman
- Family Focus-presented by Amanda Hamre
- Perseveration Annihilation: Breaking Out of the Loop-presented by John Fode

There were 147 paid registrations for the 2018 conference. Fourteen were registered using parent stipends offered by the ND Department of Human Services.

Attendance was down compared to past conferences. The committee met following the conference to review possible reasons for the decreased attendance:

- Grand Forks isn't centrally located-the conference has better attendance when it is centrally located.
- Childcare-many families struggle with finding childcare to attend the conference.
- Lack of employer sponsored continuing education funds.
- Schedule-the conference was two half days. Consider expanding to a day and a half to allow people who can only make it one day to choose a preferable date.

The committee has started preliminary planning for future conferences. The committee is proposing to move the conference to April to coincide with Autism Awareness month. The next conference will be held in Bismarck in April 2020. Additional proposed changes:

- 1 ½ days.
 - Day 1- Afternoon keynote speakers followed by a full day (Day 2) of breakout sessions and possibly shorter closing keynote speaker.
- Explore the possibility of onsite childcare (encourage/support more families to attend).
 - Collaboration with the University of Mary or Bismarck State College
- Possible Topics (based on 2018 evaluations)
 - Dealing with challenging behaviors
 - Working with Families
 - ASD and Mental Health co-morbidity
 - Transition to School
 - More advanced topics on evidence-based practices

ASD State Plan

- Workgroup Updates
 - Children's
 - Discussion held around autism resource webpage and concerns of its upkeep. Discussion of who would be responsible to house a central location for dissemination of resources, but no decision made.
 - Adults
 - Discussion held around ND Autism conference and trying to find more funding options for the keynote speakers.
 - Discussion around the public input survey-reviewing the draft survey. If there are any other suggestions for changes, it was requested that they be sent to Kodi Pinks by February 8, 2019.
 - ASD Task Force State Plan-review progress updates
 - Motion made by Teresa Larsen to approve the ASD Task Force State Plan. Seconded by Vicki Peterson. 9 yay/0 nay. Motion approved.

ASD database annual report-Kodi Pinks

Over the last three years, providers reporting ASD cases to the database began to decline, and manual entry became burdensome. The need for more effective reporting became apparent. The ND Health Information Network (NDHIN) and the North Dakota Department of Health (NDDoH) worked together on a project to improve data quality/quantity and to decrease the burden of ASD database reporting. NDDoH recruited pilot facilities to participate in the project. An automated report was developed to increase reporting of ASD cases. A trigger was developed and all HL7 compliant admissions, discharges and transfers (ADT) messages, coming from the pilot facility into the NDHIN are routed through the trigger. If the ADT message contains any ICD-10 codes used for the diagnosis of ASD, a copy of the ADT message is sent to a folder located on NDDoH's network. Maven automatically checks the folder every hour and imports any messages found in the folder. The messages are sent from the NDHIN into Maven (the ASD database) using a trigger that was built by the NDHIN staff and NDDoH staff.

Results:

Before the pilot project was implemented in 2018, submissions to the ASD database were declining. Data from October to December, for 2016 through 2018 are as follows:

- 2016: 66 cases reported from 11 facilities (average of 6 cases per facility)
- 2017: 16 cases reported from 5 facilities (average of 3.2 cases per facility)
- 2018: 39 cases reported from 1 pilot facility using NDHIN

This pilot project was also successful in its collection of patient demographic information for individuals diagnosed with ASD.

Benefits of utilizing the NDHIN for database reporting:

- Reduces the burden on facility personnel to manually fill out reports and submit.
- Reduces the amount of data entry time for both the facility and NDDoH.
- can update Maven demographic and contact data due to multiple reports per case

This is an innovative approach to collecting ASD data; however, not every facility/provider is submitting information to the NDHIN. Patients also have the option to opt out of the NDHIN. Due to these factors, an ASD report form will need to remain available.

Current Operations updates

- 2017-2019 enrollment/expenditures dashboard (located online at <https://www.nd.gov/dhs/autism/taskforce.html>)
- Waiver
 - Have offered the 96 slots to families but are struggling to receive assessments back to screen the children for eligibility.
 - In order to receive waiver services, Medicaid enrollment must be complete. Filling out and submitting the paperwork is a challenge for some families.
- Voucher
 - In January 2019, 180-day inactivity letters were sent out to four families. Three families responded. Kathy and Kaitlin will follow up with the last family to make sure they understood the letter.
 - Still taking applications for the autism voucher.
- ABA
 - Still proceeding with new ABA requests.

Survey of BCBAs-Holly Johnson

- Discussion around the length of time that it takes for board-certified behavior analysts (BCBAs) to obtain state licensure. For people with bachelor's degrees, from the start of master's level education to attain the BCBA certification to obtaining state licensure, it takes at least 2 ½ to 3 years.
- Possibility of student loan repayment for BCBAs-this could bring in more BCBAs to help with the workforce shortage.
- Forty-eight of the fifty states have acted to require meaningful coverage for the treatment of autism in state-regulated health plans. The two states that don't have mandated coverage are Wyoming and Tennessee.

Teresa Larsen made the motion to adjourn the meeting. Kodi Pinks seconded the motion. 9 yay/0 nay. Motion approved.

Meeting adjourned at 4:40 p.m.

Transcribed: 2/19/2019