

Autism Spectrum Disorder (ASD) Task Force Meeting Minutes

August 20, 2018

Task Force members present: Jennifer Flores, Dawn Hanson, Holly Johnson, Teresa Larsen, Connie Lillejord, Vicki Peterson and Kodi Pinks

Task Force members present via polycom/phone: Dr. Thomas Carver, Senator Joan Heckaman, Mary Jaeger, Carol Johnson, Nancy Ulrich-Crotty, and John Watkins

Absent: Maggie Anderson, Heather Opland, Gerry Teevens and Catherine Yeager

A quorum of Task Force members were present.

Guests (present and via polycom/phone): Kaitlin Kurtz, Krista Fremming, Trevor Stavig, Susan Gerenz, Lorena Poppe, Tom Solberg, Heather Steffl, Stephanie Nelson, Carmen Peck, Skylar Hertzog and Farrah Thoreson

Meeting was called to order at 1:05 p.m.

Review of minutes- May 2018 minutes were reviewed.

Teresa Larsen moved approval; Connie Lillejord seconded. 13 yay/0 nay: motion passed.

Presentation from Trevor Stavig, NDSU Doctor of Nurse Practice Student, on his clinical dissertation regarding ASD

- Title of his dissertation: Increasing awareness and screening of ASD in North Dakota with use of an ASD Toolkit
- Main Objectives
 - Provide useful information regarding screening and referral of ASD
 - Continue the promotion of early screening and early referral
 - Creation of a user-friendly ASD toolkit
 - Increase understanding of barriers that providers face in screening and diagnosing ASD
- In North Dakota and nationally, the average age of ASD diagnosis is higher than what experts recommended.
 - Many studies have found children showing signs earlier than 18 months of age.
 - Later diagnosis delays the process of early intervention.
- The toolkit provides screening recommendations that are peer-reviewed and scientifically validated.
- The toolkit includes:
 - A brief survey that asks providers about their awareness of the importance of screening for and diagnosing ASD and barriers they face.
 - Bright Futures Guidelines for Health Supervision of Infants, Children, and Adolescents endorsed by the American Academy of Pediatrics

- Region specific guide for resources, referrals and patient education
- Example of the Modified Checklist for Autism in Toddlers, Revised with Follow-Up (MCHAT-R/F) and how to score

Task Force Membership

- Holly Johnson is the newest member of the Task Force appointed by the Governor. She fills the behavior specialist role.

Current Operations updates:

Waiver

- There are concerns from Task Force members regarding the low waiver expenditures so far this biennium.
- There was discussion about if a child needs service management to access the waiver or could they receive respite and/or assistive technology services without service management. It was clarified that the autism waiver requires a service manager to complete the participant service plan. Respite and assistive technology are optional waiver services.
- Some providers are not taking on more children for service management and instead, putting them on a waitlist. These provider shortages are contributing to lower expenditures than budgeted.
- There are currently 50 children on the waiver waitlist. Most are either waiting for a Medicaid eligibility determination from the county or waiting to receive a diagnosis from a psychologist or psychiatrist.

ABA

- As of October 1, 2018, ND insurance companies will be required to cover applied behavior analysis (ABA) therapy for ASD. This ND Insurance Department mandate will make ABA more accessible but will also exacerbate the workforce shortages in this area. The bulletin issued by the ND Insurance Department can be found at:
<https://www.nd.gov/ndins/uploads/20/20180711Bulletin20181.pdf>.

Autism Voucher

- There was a discussion regarding families on the voucher who do not make regular purchases. Currently, the families receive a letter if they have not made a purchase within 180 days of voucher enrollment. Once the letter is sent, families are provided an additional 30 days to submit a purchase request or their voucher enrollment will be terminated so that another child may access the voucher funds.
 - Suggested change - a letter would be sent after 90 days of inactivity and families would be provided an additional 30 days to submit a purchase request. The voucher program rules are outlined in North Dakota Administrative Code, so any changes would need to

go through the Administrative Code change process. Other suggestions for changes to Administrative Code will be discussed at the October meeting.

- There was also discussion about families needing assistance on what the voucher can purchase.
 - To provide clarification to families and providers, an addition was made to the voucher purchase request form. On the back of the form, it lists the steps to request item(s) and/or service(s) and it lists what the voucher can purchase.
- There was discussion about adding case management/service management as a voucher service.

Autism Waiver renewal

- The waiver has been submitted to the Centers for Medicare and Medicaid Services (CMS) and they have up to 90 days to approve the waiver. The waiver amendment will renew the waiver for five years. Most of the comments submitted during the public comment period related to:
 - Increase the waiver age to 18.
 - Families want to use respite care while the caregiver is at work/school.
 - There is a need for more providers for waiver services.

Autism Voucher Survey

- In June 2018, a survey was sent to families who have accessed the voucher. Surveys were sent to 53 families; 10 responses were returned.
- Summary of survey responses:
 - Seven of 10 respondents agreed that they had a clear understanding of what the voucher program can be used for.
 - The most frequent response was that the families use the voucher program and the outcomes have been helpful.
 - Written comments were generally positive, indicating that families appreciate the assistance the voucher provides them.
 - A question was asked regarding how many families apply for the autism voucher program and are denied due to the family income being over 200% of the federal poverty level. For voucher year July 2017-June 2018, four families were denied; for July 2018-present, three families have been denied.

Workgroup Updates

- The Workgroup leaders gave recommendations on updates to the state plan. The workgroup leaders should send their recommendations via email to Melanie Phillips, so she can compile them into a final draft for the Task Force to approve at the October meeting.

Telemedicine

- ND Medicaid recently revised its telemedicine policy to include coverage of most services via telemedicine, unless Current Procedural Terminology (CPT) guidelines do not allow. These

changes should enable more providers to utilize telemedicine for autism services. The policy is located at: <http://www.nd.gov/dhs/info/mmis/docs/telemedicine.pdf>.

Services to children and families in rural areas

- Rural families are still having trouble receiving services including ABA and waiver services. There was a discussion on how to get services to families in the rural areas:
 - Rural differential-mileage for providers for travel to rural areas
 - Utilizing telemedicine

Training and orientation for county eligibility workers

- The Department of Human Services (DHS) is looking at modifying the application for Medicaid waiver services.
- There have been concerns regarding the varying practices at each county social service office. The issue of the eligibility workers being better trained to assist their clients was also discussed.

The Role of Developmental Disabilities Program Managers (DDPMs) in Advising Clients/Families to Move from One Waiver to Another

- It was clarified that the DDPM's role is to explain all the services and eligibility criteria for each waiver to the family and then assist the family with making the decision that would be best meet their needs.

ND ASD Conference

- The annual ND ASD Conference will be held October 24 and 25, 2018 in Grand Forks.
 - DHS could provide funding to support stipends for parents/guardians of a child(ren) with ASD or adults with ASD. Krista Fremming will communicate with Anne Carlsen Center regarding the stipends.

Letter from Senator Heckaman to Maggie Anderson

- Senator Heckaman sent a letter to Maggie Anderson requesting clarification on various items related to autism services. Maggie responded with a letter that answered the questions.
 - The Task Force reviewed the letter and the answers.

Meeting adjourned at 4:45 p.m.

Transcribed: 8.23.2018