

2017

Autism Spectrum Disorder (ASD)

Task Force

Annual Report on ASD State Plan



Overview

Pursuant to North Dakota Century Code (NDCC) 50-06-32, the Autism Spectrum Disorder (ASD) Task Force provides an annual report to the Governor and the Legislative Council regarding the status of the ASD State Plan.

ASD Task Force Members and Duties

Senate Bill No. 2174 (2009), codified as Section 50-06-32, established an Autism Spectrum Disorder (ASD) Task Force consisting of the State Health Officer or designee, the executive director of the Department of Human Services or designee, the director of special education, the executive director of the Protection and Advocacy Project or designee, and the following members appointed by the Governor:

- A pediatrician with expertise in the area of ASD;
- A psychologist with expertise in the area of ASD;
- A college of education faculty member with expertise in the area of ASD;
- A licensed teacher with expertise in the area of ASD;
- An occupational therapist;
- A representative of a health insurance company doing business in the state;
- A representative of a licensed residential care facility for individuals with ASD;
- A parent of a child with ASD;
- A family member of an adult with ASD; and
- A member of the Legislative Assembly.

Senate Bill No. 2215 (2017), codified as Section 50-06-32, added additional members to the Autism Spectrum Disorder Task Force including:

- A behavioral specialist;
- A representative who is an enrolled member of a federally recognized Indian tribe; and
- An adult self-advocate with autism spectrum disorder.

Senate Bill No. 2215 also changed the membership from “director of special education” to superintendent of public instruction (or designee).

The ASD Task Force, in accordance with NDCC 50-06-32, meets on a quarterly basis to examine the following topics:

- early intervention services
- family support services that would enable an individual with ASD to remain in the least restrictive home-based or community setting
- programs transitioning an individual with ASD from a school-based setting to adult day programs and workforce development programs
- the cost of providing services
- the nature and extent of federal resources that can be directed to the provision of services for individuals with ASD

In 2017, the Task Force formed three workgroups: an ASD State Plan workgroup as well as workgroups focusing on children and adult services. The workgroups will meet at least once in between the quarterly Task Force meetings and will discuss the following topics:

- supporting families
- transitions from childhood to adulthood
- ASD State Plan
- fiscal estimates and funding options for services/supports
- potential policy proposals

The Task Force is to develop an ASD State Plan and continue to review and periodically update or amend the plan to serve the needs of individuals with autism spectrum disorder. The Task Force is to provide an annual report to the Governor and the Legislative Council regarding the status of the ASD State Plan.

ASD State Plan Updates

The goals and activities from the 2014 ASD State Plan have been reviewed and are summarized below.

Goal: Assure that individuals with suspected ASD receive an appropriate diagnosis as soon as possible.

- **Diagnostic clinics:** There are currently diagnostic clinic sites in Grand Forks, Jamestown, Minot, and Williston and Belcourt. The North Dakota Department of Health (DoH) publishes the clinic contact information as well as the dates and locations that the clinics are held: <http://www.ndhealth.gov/cshs/clinic.htm>.
 - **Diagnostic Clinics:** These clinics include a group of professionals, which can include, a pediatrician, occupational therapist, board-certified Behavior Analyst, speech-language pathologist, psychologist and, when necessary, some clinics will include a dietician and a medical social worker. Most of the clinics are a half-day or more and sometimes families come back for a second day. Families are asked to gather multiple medical, educational, and developmental documents to send to the clinic and in many cases, the family needs to fill out numerous forms prior to the first visit.

Although, North Dakota has six major cities that provide diagnostic clinics, this number can be misleading, as clinic availability is limited. To provide perspective, following is information on upcoming 2018 clinics:

- **Minot Clinic:** Available on January 10 and November 14, 2018. Four clients total will be evaluated at these two clinics in the upcoming year.
- **Belcourt Clinic:** Available on March 7 and September 12, 2018. Four clients total will be evaluated at these two clinics. This is the first year that a clinic has been held in this community.
- **Williston Clinic:** Available on June 11, 2018. A total of two clients will be evaluated this year.

The Great Plains Interdisciplinary Autism Diagnostic Clinic (GPIC) professionals are providing the above clinics for 2018. They are able to provide these clinics through funds provided through the Special Health Services division of the Department of Health. They have started a waiting list, as their clinics are filled.

- **Jamestown Clinic:** The Anne Carlsen Diagnostic clinic is held twice a month and sees a total of 24 clients in a year. In the past year, the cost of a clinic has been

covered anywhere from \$0 up to \$1600. If a client has ND Medicaid, the payment is around \$330. The wait list is three months, although over 40 families are inquiring and beginning the process of putting together their medical packets. They will be moved to the top of the list once their medical packets are completed. At the current time, a new family would be scheduled about three months from now.

- **Fargo Clinic- Sanford Health:** The wait list to be seen in this clinic is about 2-3 months. Fargo uses a multidisciplinary approach. They see clients as they call in and can be scheduled. This clinic sees others with developmental problems, as well. Parents are given the diagnosis on the same day.
- **Grand Forks – Rehab Autism Diagnostic Clinic at Altru:** This clinic is held six times per year and features a multidisciplinary team that eliminates the need for parents to have to attend multiple appointments over different days. They also offer a screening clinic at no cost.

These are the current clinics across the state that offer multiple professionals in a multidisciplinary or interdisciplinary approach.

Parents can also find many single service providers in some of the larger ND communities (Fargo, Bismarck, Grand Forks, and Bismarck). For instance, psychologists and some doctors have experience and are competent/qualified to provide a diagnosis, while others prefer to refer to one of the above clinics where a team of professionals work together to come to a diagnosis. Since Autism cannot be diagnosed with a blood test and is based on information and observed behaviors, it is, at times, a difficult diagnosis.

- **ASD database:** In 2013, the North Dakota State Legislature adopted legislation (North Dakota Century Code 23-01-41) that requires the DoH to maintain a database of all individuals diagnosed with ASD. DoH continues to work with the community on education, screening data, and submission of the data via the web portal. Currently, there are about 480 individuals included in the database.

Goal: The Task Force will promote a centralized location and consistent message for information on ASD.

The North Dakota Department of Human Services (DHS) Autism Services website (www.nd.gov/dhs/autism) maintains information as well as links to ASD-related resources. In August 2016, DoH and DHS partnered to update the ASD resource booklet. It is available online or in printed copy upon request.

Goal: To establish a model for training and provision of support services that meet the needs of diverse stakeholders.

- DHS collaborated with the Anne Carlsen Center by supporting and serving on the planning committees for the 2017 ASD conference. Approximately 250 people attended the conference.

- Additional training includes educational opportunities available through Minot State University that are open to caregivers, providers, etc.
- DHS provided support for online training for providers, educators and caregivers.
- Family Voices of North Dakota held caregiver cafes in Dickinson and Bismarck, focusing on a resource toolkit for caregivers.
- The North Dakota Department of Public Instruction (NDDPI) held a special education conference for special education teachers and directors. NDDPI hosted a fall educators conference during October 2017 with several tracks including special education. Over 700 educators attended.

Goal: Families and providers will know and implement evidence-based strategies as a matter of practice in teaching and caring for people with ASD as well as other individually-designed strategies.

- Applied Behavior Analysis (ABA) Services were incorporated into the Medicaid State Plan, effective August 1, 2017.
- Medicaid ABA Services provide assistance to a qualifying individual with an ASD diagnosis. The services include program oversight supporting comprehensive assessment, care plan development, referral, monitoring and follow-up as well as skills training for qualifying individuals and their caregivers. Services can occur within the home, community or a provider's facility.

Goal: Assure that data on programs and services is available and used to guide the services system.

- DHS provides quarterly updates to the ASD Task Force regarding the waiver, voucher, and ABA services available within the Medicaid State Plan.
- DHS hosts monthly phone calls for providers.
- DoH provides quarterly updates on the ASD database as well as updates on diagnostic clinics.
- DHS (through its Developmental Disabilities Division) requested assistance through the Centers for Medicare and Medicaid Services Home and Community Based Technical Assistance project and via this effort, the National Association of State Directors of Developmental Disabilities Services worked with DHS to review the State's delivery system for long-term services and supports. Review of the ASD Waiver and services was included in the technical assistance. DHS has received the report and will use the report to evaluate potential changes to Medicaid waivers and service delivery over the next several biennia.

DHS Medical Services Programs for ASD

Medicaid ASD Waiver

The waiver is designed to assist individuals with a diagnosis of ASD and caregivers gain access to medical, social and educational service options. The goals of the waiver are to maximize child development and to help prevent out-of-home placements. The approved waiver services include respite, service management and technology assistance. The total waiver appropriated for the waiver for the 2017-19 biennium is \$3,363,979.

To be eligible for the waiver, children ages three through 11 with a diagnosis of ASD must qualify for Medicaid, be eligible to receive care in an intermediate care facility and live in their legally appointed caregiver's home.

Recent updates to the waiver include:

- July 2017: Increased the number of slots from 47 to 59 and increased the age through 9 years old. This amendment also removed program design and monitoring and skills training services from the waiver. The services remaining within the waiver are service management (to assist families in completing the participant care plan and to provide support to the family as needed); assistive technology (funds available to provide the child with devices or equipment that can help navigate the daily challenges of having a diagnosis of ASD); and respite (temporary relief for the primary caregiver(s)).
- December 2017: Added the 25 slots that were not filled due to the February 2016 budget allotment, and added an additional 12 slots* to bring the total available slots to 96 and increased the age through 11. This amendment changed eligibility requirement from having the evaluation and determination team determine a child's eligibility to having a psychological evaluation including an ASD diagnosis. The amendment also changed the requirement of utilizing a waiver service from monthly to quarterly. These changes were made to make access to services easier for families.
 - North Dakota Administrative Code is currently being updated to reflect the new eligibility age through age 11. Effective date of the updated rule is expected to be April 1, 2018.

*The additional 12 slots are consistently added to ensure continued Medicaid ASD Waiver coverage for children who would otherwise "age out" of the waiver. A request for the additional 12 slots has been a consistent part of the DHS budget for several biennia.

Autism Voucher Program

The autism voucher program, which is supported solely with state general fund, helps to pay for assistive technology, training and other approved support services that enhance the quality of life of children with ASD and help meet the unique needs of their families. There are currently 53 slots available per year. As a result of the 2016 budget allotment, ten slots that were approved by the 2015 Legislative Assembly were not filled. The 2017 Legislative Assembly restored the funding for the ten slots, which are part of the 53 slots available.

Between July 2016 to June 2017, 50 individuals were served with an average expenditure of \$4,398 per person. Some of the items that have been purchased for eligible individuals are stress relieving items such as chewy wristbands and necklaces, iPads, swimming lessons, memberships for activity centers, respite care, tutoring, and safety items.

North Dakota Administrative Code is being updated with an expected effective date of April 1, 2018. The reason for the update is to add clarification and reduce confusion for families accessing the voucher and for DHS in the administration of the voucher.

Medicaid State Plan – Applied Behavior Analysis (ABA) services

DHS, with guidance from CMS, pursuant to the Medicaid Early and Periodic Screening, Diagnosis and Treatment (EPSDT) benefit¹, worked to remove some of the services previously available via the Medicaid ASD waiver and move them to the Medicaid State Plan. This included applied behavior analysis (ABA) services. Medicaid autism ABA became available August 1, 2017 for individuals age birth to 21 years of age who are diagnosed with ASD and are enrolled in Medicaid.

ABA focuses on the principles that explain how learning takes place. Positive reinforcement is one such principle. When a behavior is followed by some sort of reward, the behavior is more likely to be repeated. Through decades of research, the field of behavior analysis has developed many techniques for increasing useful behaviors and reducing those that may cause harm or interfere with learning.²

Medicaid autism ABA services include program oversight supporting comprehensive assessment, care plan development, referral, monitoring and follow-up; and skills training to assist the individual with ASD in acquiring skills identified in his or her care plan.

Skills trainers can also train the individual's caregivers (parents, grandparents, others) to implement the interventions to help the individual reach his or her identified goals. Services can occur within the home, community or a provider's facility.

Families seeking ABA therapy for a Medicaid-eligible child need a documented ASD diagnosis, a current EPSDT screening, and a recommendation for ABA therapy from a primary care provider.

The total appropriated for Medicaid ABA therapy for the 2017-19 biennium is \$18,251,750.

¹ <https://www.medicaid.gov/Federal-Policy-Guidance/Downloads/CIB-07-07-14.pdf>

² <https://www.autismspeaks.org/what-autism/treatment/applied-behavior-analysis-aba>

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