

2018

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 ASD 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

The Task Force has three workgroups: an ASD State Plan workgroup as well as workgroups focusing on children and adult services. The workgroups 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 2018 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.

- Multidisciplinary diagnostic clinics: There are currently diagnostic clinic sites in Grand Forks, Jamestown, Minot and Fargo. The North Dakota Department of Health (DoH) publishes the clinic contact information as well as the dates and locations the clinics are held: <http://www.ndhealth.gov/cshs/clinic.htm>.
 - Four of the eight human service regions do not have multidisciplinary diagnostic clinics (Bismarck, Devils Lake, Dickinson and Williston). All regions report problems with access and wait lists.
 - Some individual providers including physicians and psychologists are able/willing to diagnose, but some prefer to refer patients to a multidisciplinary clinic.
- 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 just over 500 individuals included in the database.
 - In the fall of 2018, a survey was sent to North Dakota pediatricians, family medicine physicians and nurse practitioners to assess how they approach diagnosing ASD.
 - It is a challenge to get providers to report to the database, even though it is mandatory. They cite concerns about patient privacy and the time it takes to fill out the information to be submitted to the database.

Goal: The Task Force will review and provide recommendations on the current centralized location(s) 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. Task force members are able to recommend resources and links to be placed on the website.

Goal: Establish a model identifying training and education opportunities currently available that addresses the needs of diverse stakeholders.

- DHS collaborated with the Anne Carlsen Center by supporting and serving on the planning committees for the 2018 ASD conference. DHS supported stipends for adults with ASD and parents/guardians of children with ASD. Approximately 130 people attended the conference.
- Additional training includes educational opportunities available through Minot State University that are open to providers.
- Family Voices of North Dakota (FVND) held a caregiver café in Bismarck in November 2018.
- The North Dakota Department of Public Instruction (NDDPI) hosted a fall educators conference during October 2018 with several tracks including special education. Over 700 educators attended.

Goal: Identify the needs and service gaps for adults with ASD.

- The Task Force is developing a survey that will be distributed to family members of children with ASD as well as adults with ASD, to assess needs and service gaps.
- The Task Force made recommendations to the Governor on funding to support extended services. Extended services provide job coaching that helps consumers maintain integrated, competitive, community-based employment.

Goal: Strengthen supports for transitions from adolescent to adult service.

- Funding has been secured for FVND to provide two additional Caregiver Café Trainings, which focus on coordination of supports for transitions from adolescent to adult services.

Goal: Develop more opportunities for adults with ASD to be valued, contributing members of their communities based on their unique strengths, differences and challenges.

- Three sessions regarding adults with ASD were held at the 2018 ND Autism Conference.
- DHS supported stipends for the 2018 ND Autism Conference for adults with ASD and parents/guardians of children with ASD.

Goal: Ensure adults living with ASD will have a measurable increase in job opportunities paired with ongoing training and support that enables them to be successful in the workplace.

- The employment status of adults with ASD will be gathered using the Task Force survey planned for 2019.
- The ASD Task Force adult's workgroup plans to conduct an analysis of what programs (i.e. soft skills training) and tools (i.e. Got Transition) are currently being offered within school systems.

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. There are currently 96 available slots per year.

November 2018 updates to the waiver include:

- A diagnosis of ASD will be accepted from a physician, psychiatrist, nurse practitioner, clinical nurse specialist, psychologist, licensed independent clinical social worker or licensed professional clinical counselor. Previously, a diagnosis was only accepted from a psychiatrist or psychologist.
- The maximum amount of allowed services will be determined through the development of a plan of care. The plan of care is developed in collaboration between the service manager and the family, to ensure services are tailored to the child's needs. Previously, the level of care assessment determined the maximum amount of services allowed.
- Service management (case management) is available up to 16 hours per month. Previously, four hours per week.
- Families receive assistance through ND Medicaid staff for assistive technology purchases. Previously, families received assistance through a third party fiscal agent for assistive technology purchases.
- Service managers are required to make at least two home visits per year with other contacts by phone, email or telemedicine. Previously, the service manager was required to make a home visit every 90 days.

Autism Voucher Program

The autism voucher program, which is supported solely with state general funds, 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.

Between July 2017 to June 2018, 53 individuals were served with an average expenditure of \$4,995 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.

Medicaid State Plan – Applied Behavior Analysis (ABA) services

Applied behavior analysis (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.

Medicaid 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.