

## **AUTISM SPECTRUM DISORDER SERVICES - BACKGROUND MEMORANDUM**

In addition to a review of autism spectrum disorder services included as part of a study of behavioral health needs, the Human Services Committee for the 2015-16 interim has also been assigned to the following items related to services for autism spectrum disorder:

- Receive annual reports from the Autism Spectrum Disorder Task Force (North Dakota Century Code Section 50-06-32 ([Appendix A](#))).
- Receive a report from the Department of Human Services regarding the autism spectrum disorder program pilot project (Section 50-06-32.1 ([Appendix B](#))).

### **BACKGROUND**

#### **Autism Spectrum Disorder Task Force**

Senate Bill No. 2174 (2009), codified as Section 50-06-32, established an Autism Spectrum Disorder Task Force consisting of the State Health Officer, the Executive Director of the Department of Human Services, the Director of Special Education, the Executive Director of the Protection and Advocacy Project, and the following members appointed by the Governor:

- A pediatrician with expertise in the area of autism spectrum disorder;
- A psychologist with expertise in the area of autism spectrum disorder;
- A college of education faculty member with expertise in the area of autism spectrum disorder;
- A licensed teacher with expertise in the area of autism spectrum disorder;
- 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 autism spectrum disorder;
- A parent of a child with autism spectrum disorder;
- A family member of an adult with autism spectrum disorder; and
- A member of the Legislative Assembly.

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

In addition, the task force is required to develop a state autism spectrum disorder 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 required to provide an annual report to the Governor and the Legislative Council regarding the status of the state autism spectrum disorder plan.

#### **Autism Spectrum Disorder Voucher Program Pilot Project**

House Bill No. 1038 (2013), codified as Section 50-06-32.1, requires the Department of Human Services to establish a voucher program pilot project beginning July 1, 2014, to assist in funding equipment and general educational needs related to autism spectrum disorder for individuals below 200 percent of the federal poverty level from age 3 to under age 18 who have been diagnosed with autism spectrum disorder. In addition, the department is required to adopt rules addressing management of the voucher program pilot project and to establish eligibility requirements and exclusions for the voucher program pilot project. The department is required to provide a report to the Legislative Management regarding the autism spectrum disorder program pilot project.

Section 13 of 2015 Senate Bill No. 2012 provides for the continuation of Section 50-06-32.1, to require the Department of Human Services to continue the autism spectrum disorder voucher program pilot project and to report to the Legislative Management regarding the autism spectrum disorder program pilot project.

## PREVIOUS LEGISLATIVE STUDIES 2009-10 Interim

During the 2009-10 interim, the Autism Spectrum Disorder Task Force met several times; reviewed legislation, other states' autism spectrum disorder information, plans, and funding mechanisms; formed five workgroups focused on comprehensive analysis, evidence-based services, training and education, infrastructure, and funding structures; and developed, disseminated, and summarized a statewide autism spectrum disorder needs assessment survey. The results of the survey indicated current autism spectrum disorder services are inadequate, information is scarce, and training is needed for parents and professionals. The survey results also noted North Dakota does not have a funding mechanism that is accessible and seamless.

The task force established an initial state plan (2010) based on the following facts and guiding principles:

- Autism spectrum disorders are disorders with tremendous variability within the population.
- Autism spectrum disorders occur in all geographic, ethnic, racial, and socioeconomic groups.
- Every child in North Dakota with an autism spectrum disorder deserves an accurate and timely diagnosis.
- North Dakota children with an autism spectrum disorder diagnosis deserve appropriate, and timely treatment, and appropriate education in the least restrictive environment according to their individual needs.
- People with autism spectrum disorder benefit from an individualized approach based on their unique needs. This can range from minimal or no formal support to intensive coordinated personal care and behavioral supports.
- Families and caregivers of people with autism spectrum disorder deserve and benefit from quality information and supportive services.
- Health, transportation, education, and law enforcement personnel provide services more effectively when appropriately educated about autism spectrum disorder.
- Adults with autism spectrum disorder benefit from employment, inclusive community living options, and supports of their choosing.

The state plan enacted during the 2009-10 interim contains seven categories each with a vision and related recommendation. The following is a summary of the visions and recommendations included in the state plan:

Categories	Visions	Recommendations
Early identification and screening	All children in North Dakota will receive screening for a developmental delay within the first year of life by a qualified health care professional. In the second year of life, all North Dakota children will receive a screening by a qualified health care professional for autism spectrum disorder as recommended by the Centers for Disease Control and Prevention (CDC) and the American Academy of Pediatrics.	<ul style="list-style-type: none"> <li>• Promote awareness of CDC screening tools and resources</li> <li>• Training in and the subsequent use of autism screening tools for health care professionals, including Indian Health Service, should be made available to allow all children to be screened for an autism spectrum disorder in the second year of life</li> <li>• Awareness materials and early identification and screening information on the characteristics of autism spectrum disorders should be made available to ensure timely referrals for young children even before a definitive diagnosis. For those children who are identified with possible autism spectrum disorder, a diagnostic consultation and appropriate evaluation should occur within state and federal timelines by trained professionals.</li> <li>• Ensure children with a suspected autism spectrum disorder wait no longer than two months for a diagnostic consultation by a trained professional and receive a thorough diagnostic assessment within six months.</li> <li>• Increase the use of telemedicine in diagnostic assessments of children in rural areas of North Dakota</li> </ul>

Categories	Visions	Recommendations
Appropriate and effective practices	Evidence-based intervention services will be readily and consistently available for all North Dakotans diagnosed with an autism spectrum disorder regardless of age, culture, socio-economic level, or geographic location. The key to designing an effective program or treatment lies in assessing the person's present level of performance and developing appropriate goals and outcomes with family and individual input and participation. Much more important than the name of the program or treatment utilized is how the environment and program strategies allow implementation of the person's goals. Thus, effective services may vary considerably depending on age, cognitive and language levels, behavioral needs, educational and vocational needs, and family priorities.	<ul style="list-style-type: none"> <li>• Provide a comprehensive and uninterrupted system of services to individuals across the lifespan</li> <li>• Adopt standards for autism spectrum disorder practices in North Dakota that identify appropriate and effective practices for individuals with an autism spectrum disorder</li> <li>• Maximize funding available to local communities for the provision of intensive supports to individuals with autism spectrum disorder</li> <li>• Ensure training programs for service providers and families are developed by professionals knowledgeable in the latest evidence-based interventions and delivery techniques</li> <li>• Ensure trained professionals are available to provide appropriate and effective services to all North Dakotans with an autism spectrum disorder</li> <li>• Autism spectrum disorder waiver expansion for coverage across the lifespan</li> </ul>
Quality providers	Qualified personnel sufficient to meet the needs of North Dakotans with autism spectrum disorder will be available throughout the state.	<ul style="list-style-type: none"> <li>• Provide financial incentives for students pursuing an advanced degree or certificate with an emphasis in autism spectrum disorder</li> <li>• Provide incentives for current and future professionals to further their knowledge and expertise in autism spectrum disorder and to provide services to individuals with autism spectrum disorder</li> <li>• Ensure adequate continuing education opportunities and requirements are in place to guarantee that providers maintain current knowledge in autism spectrum disorder</li> <li>• Work with child care licensing administrators to increase child care options in North Dakota for children and youth with autism spectrum disorder</li> <li>• Develop a process to recognize expertise in evidence-based interventions and supports for children and adults with autism spectrum disorder</li> </ul>
Funding issues	Funding should be available for early identification and definitive diagnosis of autism spectrum disorders in North Dakota. For every North Dakotan with an autism spectrum disorder diagnosis, adequate funding shall provide access to appropriate early evidence-based intervention and ongoing support. Families, public schools, state and federal programs, and private insurance companies will play a responsible, proactive role in assuring the accomplishment of this goal.	<ul style="list-style-type: none"> <li>• Create specific funding mechanisms across service systems to support providers of high-cost intensive services to individuals with autism spectrum disorder</li> <li>• Expand the number and age range of individuals and scope of services in autism spectrum disorder waivers</li> <li>• Expand health care coverage for individuals with autism spectrum disorder</li> </ul>
Information access	All North Dakotans will have ready access to a centralized, comprehensive, dynamic source of information regarding autism spectrum disorders, including appropriate and effective practices, and the availability of state and local resources, including funding options.	<ul style="list-style-type: none"> <li>• Partner with the North Dakota Center for Persons with Disabilities to develop and maintain a comprehensive autism spectrum disorder website, which serves as the first stop for autism spectrum disorder information</li> <li>• Raise awareness and identify the importance of maintaining 2-1-1 information line</li> <li>• Identify and explore Internet access options for individuals with autism spectrum disorder</li> </ul>

Categories	Visions	Recommendations
Family support	All North Dakota families affected by autism spectrum disorder will have access to supportive services. These services will enable them to effectively care for and nurture each other while maintaining their family continuity. Each family member's needs will be acknowledged and addressed. People will better understand autism spectrum disorder so that families thrive and are accepted by their communities. Individuals with autism spectrum disorder will have a bright future.	<ul style="list-style-type: none"> <li>• Provide incentives for family support provider agencies to assist families in locating and understanding service and support options</li> <li>• Provide culturally diverse and accessible resources</li> <li>• Pursue a routine autism spectrum disorder state conference representing support networks, state agencies, private providers, health care providers, and family support to present comprehensive information on the state of autism spectrum disorder in North Dakota</li> <li>• Create public awareness regarding autism spectrum disorder</li> <li>• Increase training opportunities for community clubs, parks and recreation, and other organizations on autism spectrum disorder</li> <li>• Pursue incentives for training for emergency responders on appropriate techniques for crisis intervention with individuals with autism spectrum disorder</li> <li>• Research the benefits and challenges regarding the establishment of an autism spectrum disorder registry to better distribute information to individuals with autism spectrum disorder and to better identify incidence of autism spectrum disorder leading to better resource allocation</li> <li>• Identify the needs and clarify the benefits of increased respite care</li> <li>• Increase awareness of impact on families</li> <li>• Increase awareness of increased safety risks for individuals with autism spectrum disorder</li> <li>• Increase training, education, and funding to better support individuals and their families and communities in the areas of recreation, independent living, and employment</li> <li>• Pursue alternative options to support individuals in rural areas through technology connections with support agencies</li> </ul>
Accountability	N/A	<ul style="list-style-type: none"> <li>• The task force concluded mechanisms may need to be established to assure ongoing accountability for the implementation of its recommendations.</li> </ul>

**2011-12 Interim**

During the 2011-12 interim, the Autism Spectrum Disorder Task Force met several times; reviewed legislation, other states' autism spectrum disorder information, plans, and funding mechanisms; developed, disseminated, and summarized a statewide autism spectrum disorder needs assessment survey; established an initial state plan; and provided the following prioritized recommendations regarding autism spectrum disorder services to the Human Services Committee:

Rank	Description	Explanation	Estimated Biennial Costs
1	Add a state autism coordinator and assistant	Two new full-time equivalent (FTE) positions responsible for implementing a "one-stop shop" for information and services for individuals with an autism spectrum disorder, developing a state outreach plan, holding regional meetings, holding an annual conference, and developing a protocol for use after screening	\$494,135

Rank	Description	Explanation	Estimated Biennial Costs
2	Provide comprehensive training funds	A statewide training effort, including physician training, regional training, and parent training, led by the state autism coordinator in coordination with key agencies	\$158,032
3	Expand and refocus the autism spectrum disorder Medicaid waiver	Expansion of the department's autism spectrum disorder Medicaid waiver to cover individuals from age 3 through end of life and to provide services, such as evidence-based practices, intervention coordination, in-home support, equipment and supplies, home monitoring, residential supports and services, extended vocational supports, and behavioral consultation	The department's current developmental disabilities traditional waiver is budgeted on each person's services and support costing an average of \$27,239 per year for waiver services.
4-5	Increase behavioral analysts	Increase the number of professionals delivering behavioral analyst services by providing funding support for 16 people (two in each region) to complete the St. Paul online board-certified behavioral analyst program to include the required supervision up to the point of taking the certification	\$198,872
4-5	Establish dedicated diagnostic, evaluation, and service planning teams	Provide funding for evaluation, diagnostic, and service planning teams comprised of a physician, occupational therapist, physical therapist, certified behavioral analyst, and family support member. The teams must interact with regional coalitions, state agencies, and the Autism Spectrum Disorder Task Force and provide timely referral and outcome reports.	Evaluations and screenings currently range from \$1,725 to \$5,045 per child.  The estimated cost of screening eight children in each of the eight regions would range from \$110,400 to \$322,880.  The estimated cost of screening 16 children in each of the eight regions would range from \$220,800 to \$546,760.
6	Mandate private insurance coverage for autism care and treatment	Eliminate the exclusions for autism care and treatment in health insurance policies	Senate Bill No. 2268 (2011), as introduced, provided for this recommendation. The fiscal note submitted for this bill estimated a cost of approximately \$5.8 million for state government for the 2011-13 biennium.
7	Establish an autism spectrum disorder registry	Develop and implement an autism spectrum disorder registry	\$200,646

**2013-14 Interim**

**Autism Spectrum Disorder Plan**

During the 2013-14 interim, the Autism Spectrum Disorder Task Force met quarterly and provided recommendations on autism waiver slot prioritization as it transitioned to the new waiver, received reports on the voucher program implementation, received information on the various training provided through the Department of Public Instruction, received updates on the registry development and autism website, and provided the following goals of the task force:

- Assured that individuals with suspected autism spectrum disorder receive an appropriate diagnosis as soon as possible;
- Created a centralized location for information on autism spectrum disorder;
- Provided a consistent message and information on autism spectrum disorder;
- Established a model for training and provision of support services that met the needs of diverse stakeholders;
- Received feedback from people with autism spectrum disorder and their families and providers which indicates satisfaction with interventions and supports available;
- Instructed families and providers to implement evidence-based strategies as a matter of practice in teaching and caring for people with autism spectrum disorder as well as other individually designed strategies; and

- Assured that data is available and used to guide the services system.

**Autism Spectrum Disorder Voucher Program Pilot Project**

During the 2013-14 interim, the autism spectrum disorder voucher program pilot project went into effect to serve families with an income below 200 percent of the federal poverty level, with a child under the age of 18 with an autism spectrum disorder diagnosis. The Department of Human Services reported to the committee, the following:

- Each qualifying child is eligible for up to \$12,500 per year.
- Applications for the autism voucher are available online, and as of August 2014, 14 voucher applications had been submitted.
- Applicants expressed interest in items and services which included autism-specific camps, a service dog to detect seizures and prevent wandering, an iPad, a note-taking device, respite care, tutoring, and job coaching.

ATTACH:2