

STUDY OF THE AUTISM SPECTRUM DISORDER - BACKGROUND MEMORANDUM

The Human Services Committee has been assigned various responsibilities relating to the diagnosis and treatment of, care for, and education of individuals with autism spectrum disorder. These responsibilities include:

- A study of the current system for the diagnosis of, early treatment of, care for, and education of individuals with autism spectrum disorder as directed in Section 2 of 2011 Senate Bill No. 2268 ([Appendix A](#)). The study must include a review of a sliding fee scale for payment of services and the value of services provided. The study must consider the recommendations of the Autism Spectrum Disorder Task Force and must seek input from stakeholders in the private and public sectors, including families affected by autism spectrum disorder, insurers, educators, treatment providers, early childhood service providers, caretakers, and nonprofit intermediate care facilities for individuals with intellectual disabilities.
- Receive an annual status report relating to the autism spectrum disorder plan from the Autism Spectrum Disorder Task Force (North Dakota Century Code Section 50-06-32 ([Appendix B](#))).
- Receive a report from the Department of Human Services before September 30, 2012, regarding the department's preliminary findings and recommendations concerning its regional autism spectrum disorder centers of early intervention and achievement pilot program, and a report from the department before December 31, 2012, summarizing the status of the pilot program and any findings and recommendations (Section 1 of Senate Bill No. 2268 ([Appendix A](#))).

AUTISM SPECTRUM DISORDER

An autism spectrum disorder is a developmental disorder that causes significant impairments in the areas of socialization, learning, communication, behavior, and play skills. The deficiencies can lead to serious behaviors and can interfere with daily living. Characteristics do not usually manifest until between one and three years of age. The spectrum includes autism, Asperger's syndrome, pervasive developmental disorder - not otherwise specified, Rett's syndrome, and childhood disintegrative disorder. Symptoms and levels of impairments vary widely.

AUTISM SPECTRUM DISORDER TASK FORCE

Background Information

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 is to 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.

The task force is 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 to provide an annual report to the Governor and the Legislative Council regarding the status of the state autism spectrum disorder plan.

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 that current autism

spectrum disorder services are inadequate, information is scarce, and training is needed for parents and professionals. The survey results also noted that 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, 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 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"> • Promote awareness of CDC screening tools and resources • 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. • 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. • 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. • Increase the use of telemedicine in diagnostic assessments of children in rural areas of North Dakota
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	<ul style="list-style-type: none"> • Provide a comprehensive and uninterrupted system of services to individuals across the lifespan • Adopt standards for autism spectrum disorder practices in North Dakota that identify appropriate and effective practices for individuals with an autism spectrum disorder • Maximize funding available to local communities for the provision of intensive supports to individuals with autism spectrum disorder

	depending on age, cognitive and language levels, behavioral needs, educational and vocational needs, and family priorities.	<ul style="list-style-type: none"> • Ensure training programs for service providers and families are developed by professionals knowledgeable in the latest evidence-based interventions and delivery techniques • Ensure that trained professionals are available to provide appropriate and effective services to all North Dakotans with an autism spectrum disorder • Autism spectrum disorder waiver expansion for coverage across the lifespan
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"> • Provide financial incentives for students pursuing an advanced degree or certificate with an emphasis in autism spectrum disorder • 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 • Ensure adequate continuing education opportunities and requirements are in place to guarantee that providers maintain current knowledge in autism spectrum disorder • Work with child care licensing administrators to increase child care options in North Dakota for children and youth with autism spectrum disorder • Develop a process to recognize expertise in evidence-based interventions and supports for children and adults with autism spectrum disorder
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"> • Create specific funding mechanisms across service systems to support providers of high-cost intensive services to individuals with autism spectrum disorder • Expand the number and age range of individuals and scope of services in autism spectrum disorder waivers • Expand health care coverage for individuals with autism spectrum disorder
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"> • Partner with 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 • Raise awareness and identify importance of maintaining 211 information line • Identify and explore Internet access options for individuals with autism spectrum disorder • Provide incentives for family support provider agencies to assist families in locating and understanding service and support options • Provide culturally diverse and accessible resources • Pursue a routine autism spectrum disorder state conference representing support networks, state agencies, private providers, health care providers, family support to present comprehensive information on the state of autism spectrum disorder in North Dakota

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"> • Create public awareness regarding autism spectrum disorder • Increase training opportunities for community clubs, parks and recreation, and other organizations on autism spectrum disorder • Pursue incentives for training for emergency responders on appropriate techniques for crisis intervention with individuals with autism spectrum disorder • 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 • Identify the needs and clarify the benefits of increased respite • Increase awareness of impact on families • Increase awareness of increased safety risks for individuals with autism spectrum disorder • Increase training, education, and funding to better support individuals and their families and communities in the areas of recreation, independent living, and employment • Pursue alternative options to support individuals in rural areas through technology connections with support agencies
Accountability	N/A	<ul style="list-style-type: none"> • The task force concluded that mechanisms may need to be established to assure ongoing accountability for the implementation of its recommendations.

DEPARTMENT OF HUMAN SERVICES - AUTISM SPECTRUM DISORDER MEDICAID WAIVER

The Legislative Assembly in 2009 provided funding of \$1.2 million, of which \$450,000 was from the general fund, for implementing a home and community-based care waiver to provide intensive support for young children who have a diagnosis of autism spectrum disorder. The department received approval for the waiver from the Centers for Medicare and Medicaid Services in November 2010. The waiver builds on existing services available to children and their families and provides services such as training, service coordination, and access to in-home support staff to help provide structured activities focusing on communication, behavior, and other needs, to 30 children birth to age 5. Children qualify based on diagnosis and the child's income.

DEPARTMENT OF HUMAN SERVICES - REGIONAL AUTISM SPECTRUM DISORDER CENTERS OF EARLY INTERVENTION AND ACHIEVEMENT PILOT PROGRAM

Senate Bill No. 2268, approved by the Legislative Assembly in 2011, provides that the Department of Human Services may use up to \$200,000 of its

legislative appropriation for the 2011-13 biennium to establish and operate a regional autism spectrum disorder centers of early intervention and achievement pilot program. The pilot program must provide a matching grant to a qualified applicant that is a nonprofit intermediate care facility for individuals with intellectual disabilities which is licensed by the department. A qualified applicant is to establish the availability of \$1 of nonstate, cash matching funds for each grant dollar awarded. The source of matching funds must be funds of the applicant. A qualified applicant is to submit a plan for the delivery and funding of skilled services to individuals with autism spectrum disorder who reside within the applicant's service region. The plan must provide for the establishment of a regional autism spectrum disorder center of early intervention and achievement in a city with a population of more than 10,000. As a condition of a grant award under this program, a qualified applicant is to agree to collaborate with the department in developing and implementing the plan as well as postaward monitoring by the department.

The department is to report to the Human Services Committee before September 30, 2012, regarding the preliminary findings and recommendations concerning the regional autism spectrum disorder centers of early intervention and achievement pilot program, and before December 31, 2012, summarizing the status of

the pilot program and any findings and recommendations.

PROPOSED STUDY PLAN

The committee may wish to proceed with this study as follows:

1. Receive information from families affected by autism spectrum disorder, insurers, educators, treatment providers, early childhood service providers, caretakers, and nonprofit intermediate care facilities for individuals with intellectual disabilities regarding the diagnosis and early treatment of, care for, and education of individuals with autism spectrum disorder.
2. Receive the following information from the Department of Human Services:
 - a. Information regarding services provided by the department for individuals with autism spectrum disorder, including Medicaid services and services under the autism spectrum disorder waiver.
 - b. An annual status report relating to the autism spectrum disorder plan and any related recommendations from the Autism Spectrum Disorder Task Force.
 - c. Preliminary findings and recommendations concerning its regional autism spectrum disorder centers of early intervention and achievement pilot program by June or July 2012 and a status report on the pilot program and any findings and recommendations by October 2012.
3. Receive information from the Department of Public Instruction regarding education of individuals with autism spectrum disorder.
4. Review of a sliding fee scale for payment of services and the value of service provided.
5. Develop committee recommendations and prepare any legislation necessary to implement the committee recommendations.
6. Prepare a final report for submission to the Legislative Management.

ATTACH:2