Needs: Autism Spectrum Disorder (ASD) is a complex, lifelong neuro-developmental disability typically appearing during the first three years of life, affecting increasing numbers of ND children and families. The number of children identified as having Autism in special education has increased dramatically\(^1\) at the same time that the school-aged population has decreased by 12%.\(^2\)

Early screening, diagnosis, and intervention are essential to provide optimal outcomes for children with autism and related disabilities. Many physicians and other health care providers, health insurers, legislators, educators, child care providers, families, and other important stakeholders lack current knowledge of autism, awareness of evidence-based treatment options, and the resources available to provide effective treatment.

According to the ND Autism Planning group, this lack of awareness may contribute to physician hesitancy to diagnose; increase the unwillingness of insurers to finance care; impact workforce development and infrastructure and create a burden for families who must navigate their child's education health care and transition to adult life.

Two important initiatives have been submitted during the 2009 Legislative Session to address these needs.

1. **Create a State Plan on Autism:** SB 2174 provides for the creation of an ASD task force to examine early intervention, family support and transition services, examine 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.

Why does ND need a State Plan on Autism?

- Autism Spectrum Disorders are complex disorders that require a coordinated multi-agency response
- The incidence of ASD in ND is rising and cannot be attributed solely to better or earlier diagnosis
- Access to Federal resources to combat autism will not be available to ND until a state plan is created
- Agencies lack information of available services and may duplicate or fail to address gaps in services.
- Partners have growing concerns about the limited infrastructure that is currently in place to address the unique challenges created by ASD that now face ND families, schools, providers and communities.

2. **Create an Autism Waiver:** The NDDHS Budget provides for development of an **autism waiver** to maximize use of state and federal resources needed to provide the intensive early intervention services that are needed by children with ASD and their families.

Why establish an Autism Waiver?

- A waiver will allow the DHS to provide early intervention services for children with autism
- The current Developmental Disabilities waiver limits services to children with intellectual disabilities and 30% to 50% of children with ASD do not have intellectual disabilities.
- The current infant development model is not designed to provide intensive-in-home behavior intervention needed by children with ASD. Many children with ASD are not diagnosed until after 3 years of age. A waiver will extend services to children between the ages of 3-5.

FAMNET – a rural healthcare network
Email: Cathy Haarstad cathy.haarstad@minotstateu.edu

\(^1\) The CDC estimates that 1 in 150 8 year old children had ASD in 2007, based on Autism and Developmental Disabilities Monitoring (ADDM) Network. Most states participating in the network had a prevalence range of 5.2 – 7.6 per 1,000 8 year-old children. North Dakota estimates can be calculated using this range (5.2-7.6/1,000) multiplied by the population of children age 0-18 in North Dakota in 2008.