Testimony for Human Services Committee Department of Human Services Autism Spectrum Disorder (ASD) Task Force and Pilot Project September 12, 2019

Chairman Rohr, members of the Human Services Committee, I am Krista Fremming, Assistant Director of the Medical Services Division for the Department of Human Services (DHS) and Chair of the Governor's Autism Spectrum Disorder (ASD) Task Force. North Dakota Century Code chapter 50-06-32 requires the Task Force to provide an annual report to the Governor and the Legislative Council regarding the status of the ASD Task Force State Plan as well as a report on the ASD program pilot project. I appear to provide information on both of these topics.

The ASD Task Force was established in 2009 by Senate Bill 2174. The Task Force members include the state health officer, or the officer's designee; the director of the department of human services, or the director's designee; the superintendent of public instruction, or the superintendent's designee; the executive director of the protection and advocacy project, or the director's designee; and the following members who are 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 behavioral specialist;
- A licensed teacher with expertise in the area of ASD;
- An occupational therapist;
- A representative of a health insurance company doing business in this state;

- A representative of a licensed residential care facility that provides care and services to individuals with ASD;
- A representative who is an enrolled member of a federally recognized Indian tribe;
- An adult self-advocate with ASD;
- A parent of a child with ASD;
- A family member of an adult with ASD; and,
- A member of the legislative assembly.

The Task Force meets quarterly to discuss 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; and,
- the nature and extent of federal resources that can be directed to the provision of services for individuals with ASD.

DHS maintains a website to publish information on Task Force activities http://www.nd.gov/dhs/autism/taskforce.html.

The website includes the Task Force meeting schedule, previous meeting minutes, reports and the ASD State Plan.

The ASD State Plan is developed and implemented by the Task Force.

There are two workgroups for children and adults made up of Task Force members as well as other stakeholders. The workgroups meet between Task Force meetings to review the State Plan, develop policy

recommendations and plan for future activities. The State Plan goals and the progress toward those goals include:

- I. <u>Children: Birth Through Age 18</u>
- Assure that individuals with suspected ASD receive an appropriate diagnosis as soon as possible.
 - The Task Force gathered information regarding multidisciplinary clinics being held across the state to assess access, waiting lists and how the clinics are funded. Although arena style (where all providers are in the room at the same time) multidisciplinary clinics are best practice for diagnosis of ASD, most health care payers do not cover them. The Task Force is investigating how more clinics might be funded.
- Review and provide recommendations on the current centralized location(s) for information on ASD.
 - Currently, the DHS website hosts the ASD Task Force webpage. The Task Force has made recommendations on additions to the webpage and ways to drive more traffic to the webpage.
- Establish a model identifying training and education opportunities currently available that address the needs of diverse stakeholders.
 - In spring 2019, the Task Force conducted a stakeholder survey to assess training needs. Over the next year, trainings will be offered to families, providers and the public on a variety of topics and in a variety of settings (online, in person, conferences/workshops, etc.).
- II. Adults: Age 18 and up (including transition age)
- Identify the needs and service gaps for adults with ASD.
 - Employment supports were identified as a need for adults with ASD. The Task Force recommended that the 2019

Legislative Assembly provide funding for 24 additional Extended Services slots for adults with ASD, to assist them with maintaining employment. The legislature adopted this recommendation and the new slots will be available in January 2020.

- Strengthen supports for transitions from adolescent to adult services.
 - Several workshops across the state have been delivered to families that focus on transition issues.
- Develop more opportunities for adults with ASD to be valued, contributing members of their communities based on their unique strengths, differences and challenges.
 - The adult workgroup of the Task Force is developing a public awareness campaign to help the public understand the challenges adults with ASD face.

I will also provide an update on the ASD program pilot project, also known as the ASD voucher program. The voucher program was established in 2014 to assist with funding equipment, assistive technology, respite care and other supports. The voucher is for families with children diagnosed with ASD between the ages of three and 18 whose household incomes are up to 200 percent of the federal poverty level. Children who receive voucher services may not also receive Medicaid waiver services.

The ASD voucher has filled gaps for many families over the past five years, but changes are needed to maximize program resources. During the 2017-19 biennium, about 30 percent of the program appropriation was expended. The 2019 Legislative Assembly authorized DHS to

consider administrative code changes that include a voucher that is solely for technology support and one solely for in-home supports; adding case management or parent-to-parent support as an allowable service for voucher funds; and reducing the amount of time during which a household may use approved voucher funds. DHS consulted with the ASD Task Force on proposed administrative code changes which will go into effect on April 1, 2020. These changes should ensure that more families are able to receive services and assistance to benefit their children with ASD.

This concludes my testimony. I would be happy to answer any questions.