

## How private is the personal information being collected?

The NDDoH is committed to protecting the privacy and confidentiality of individuals reported into the database. All personal information is kept in a secured environment that is password protected. Strict security precautions are used to prevent outside access to the information and only those authorized by the NDDoH will be able to view the data. The NDDoH follows all rules required by the Health Insurance Portability and Accountability Act of 1996 (HIPAA).

## Why should an individual be reported into the database?

There has been increased attention on the frequency of ASD diagnoses in the United States. At this time, there is no clear understanding of how many individuals have ASD in North Dakota that may need services. The information that is collected in the database will help shape appropriate policy and practices to improve services and support for people with ASD.



## North Dakota Autism Spectrum Disorder (ASD) Database

### Information for Families



**For more information, contact:**

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R: 5-2015



## What is Autism Spectrum Disorder (ASD)?

ASD is a developmental brain disorder that affects a person's behavior, communication and social skills. Signs of ASD begin during early childhood and typically last throughout a person's life. The severity of symptoms is different in each person and the symptoms may change in response to early intervention, growth and development.

A diagnosis of ASD includes several conditions that used to be diagnosed separately: Asperger Syndrome, Autistic Disorder, Childhood Disintegrative Disorder (CDD), and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS).

## What is the Autism Spectrum Disorder Database?

In 2013, the North Dakota Legislature passed a law (NDCC chapter 23-01-41) that requires the North Dakota Department of Health (NDDoH) to create and manage a database which includes a record of all individuals diagnosed with ASD. The information collected will be used to complete epidemiologic surveys, research and analysis, and to provide services to individuals with an ASD.



## How are individuals reported into the database?

After an individual has been diagnosed with ASD, a physician, psychologist, health care professional, or their designee will report the individual by completing a specific form and submitting it to the NDDoH. Only individuals who are North Dakota residents or whose parent/guardian is a resident of North Dakota will be reported.

## What information will be in the database?

The database contains the following:

- Demographics such as the individual's date of birth, gender and race
- Contact information for the individual and the parents/guardians
- Information about the diagnostician and the person submitting the form
- Information about the tools that were used to make the diagnosis

## Why is personal information being collected?

Personal information is collected to:

- Prevent duplications in the database
- Update data over time so the information continues to be accurate

## Do individuals have to be reported into the database?

Yes, reporters are required by law to report ASD diagnoses into the database. Individuals and parents/guardians cannot opt out of reporting. Signed consent is not required.

