

Why is the NH Registry for ASD Important?



New Hampshire was the second state in the nation to establish a legislatively mandated, state wide registry for ASD. A unique public health initiative, the NH registry not only counts the number of new cases, but tracks the average age at which a definitive diagnosis is made. Our efforts will help us understand more about the incidence of this challenging condition and how healthcare systems can best insure early and proper identification, build evidence based practices, create policy, enhance the workforce, and provide supports that will positively impact the lives of individuals with ASD & their families.

Reporting Requirements

In compliance with the state law RSA 171-A:30 and state administrative rule He-M 501.

- The New Hampshire registry applies to all cases where a definitive diagnosis has been made. Suspicion of ASD and provisional diagnosis should **NOT** be reported.
- The person with the disorder must live in the State of New Hampshire at the time of diagnosis.
- The age of the individual and the presence of co-occurring conditions do **not** rule out the requirement to report the diagnosis.
- Ideally, a diagnosis of a NH state resident, made by an out of state providers , will be added to the registry.
- Reporting occurs using the online reporting form found at http://business.nh.gov/dhhs_autism/Autism.aspx.

THE NH REGISTRY FOR AUTISM SPECTRUM DISORDERS

NH Department of Health & Human Services
Bureau of Developmental Services
105 Pleasant Street
Concord, NH 03301-3857

Phone: (800) 852-3345, Ext. 4533(NH only)
(603) 271-4533

<http://www.dhhs.nh.gov/dcbcs/bds/registry.htm>

The New Hampshire Registry for Autism Spectrum Disorders (ASD)

Making Early Identification Count

THE NH REGISTRY FOR
AUTISM SPECTRUM DISORDERS
Website: <http://www.dhhs.nh.gov/dcbcs/bds/registry.htm>



Required Reporters

ASD is a reportable condition, a physician, licensed clinician psychologist, or other healthcare professional that diagnoses a New Hampshire resident with Autism Spectrum Disorder (ASD) must report that diagnosis to the New Hampshire Registry for Autism Spectrum Disorder, using the online reporting form found at http://business.nh.gov/dhhs_autism/Autism.aspx

The New Hampshire Registry for Autism Spectrum Disorders

What information does the NH Registry include?

The NH Registry was carefully designed to track *only* the information necessary to answer three questions: How many individuals are diagnosed each year in NH? At what age is the diagnosis typically made? When considering factors such as geographic region or the type of healthcare professional making the diagnosis, do any patterns emerge that tell us more about how NH families access early developmental screening and evaluation.

Privacy is of critical importance, and no names or other identifying information will be collected. Parents will not — and *cannot* — be contacted because a provider making the diagnosis has registered their child's condition. The provider, indicates what the diagnosis is, the individual's date of birth, the date of the diagnosis, and the individual's NH town of residence .



How can a registry help individuals with ASD and their families?

The purpose of the registry is to improve current knowledge and understanding of ASD and its incidence in New Hampshire.

Data from the New Hampshire Registry continues to have an impact on federal and state efforts regarding education in public schools, developmental services, community mental health, vocational supports and even insurance coverage.

Who will have access to the information collected in the NH Registry for ASD and how will this information be used?

The total number of new cases each year will be shared with agencies that need the information for planning services and supports to individuals with ASD. The information will be broken down by the age of the diagnosis, region in which the child lives, and the type of health care professional making the diagnosis.

Among the agencies interested in the data collected by the NH Registry are the NH Bureau of Developmental Services, and the Department of Education Office of Special Education. Annual results will be published <http://www.dhhs.nh.gov/dcbcs/bds/registry.htm>

It is important to know that *no individual data will ever be reported.*

Does the NH Registry for Autism Spectrum Disorder comply with HIPAA?

Yes, registries are considered public health authorities when their duties are mandated by state laws.

Under HIPAA, a “Public Health Authority” is defined as “an agency or authority of the US, a State or territory, a political sub division of a state or territory, or an Indian tribe, or a

person or entity acting under a grant of authority from or contract with such public agency, including the employees or agents of such public agency or its contractors or persons or entities to whom it has granted authority, that is responsible for public health matters as part of its official mandate. (1)

As a “public Health Authority”, registries are “authorized by law to collect or receive such information from the purposes of preventing or controlling disease, injury , vital events such as birth or death, and the conduct of public health surveillance, public health investigations and public health interventions. (2)

(1) C.F.R. 164.502

(2) C.F.R. 164.512

