

Why is the NH Registry for ASD Important?



New Hampshire is the second state in the nation to establish a legislatively mandated, state-wide registry for all newly diagnosed cases of autism spectrum disorder. A unique public health initiative, the NH Registry will not only tell us how many children are diagnosed with ASD each year, but how early in life this neurological condition is typically identified in our state. Early screening and intervention are crucial to ameliorating the symptoms of ASD. As we learn more about diagnostic patterns in NH, the Registry will help guide public health policy toward better outcomes for children affected by ASD and their families.

The New Hampshire Registry for Autism Spectrum Disorders

Making Early Identification Count

THE NH REGISTRY FOR AUTISM SPECTRUM DISORDERS

Website: www.dhhs.state.nh.us/dhhs/bds



THE NH REGISTRY FOR AUTISM SPECTRUM DISORDERS

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

For Questions about Accessing the Registry,
Please Contact Peggy Sue Greenwood
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The New Hampshire Registry for Autism Spectrum Disorders

Autism Spectrum Disorder (ASD) is a reportable condition in New Hampshire. Beginning Nov. 1, 2008, a physician, licensed clinical psychologist or other healthcare professional that diagnoses a NH resident with ASD must report that diagnosis to the NH Registry for ASD using an on-line reporting form.

How does the Registry define ASD?

For purposes of this registry, the specific conditions that must be reported are Autistic Disorder, Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS), Asperger Disorder, Rett's Disorder, and Childhood Disintegrative Disorder as defined in the *Diagnostic & Statistical Manual of Mental Disorders, Fourth Edition, Text Revision* (DSM-IV-TR). Additionally, the patient must be a NH resident at the time of diagnosis.

The NH Registry is housed and managed by the NH Bureau of Developmental Services in Concord, NH. Additional information and the can be found at www.dhhs.state.nh.us/dhhs/bds.



How common are Autism Spectrum Disorders ?

Although now widely recognized as an important public health issue, we do not know exactly how many individuals there are with ASD. In 2007, the Centers for Disease Control released data indicating 1 in 150 eight-year-old children in multiple areas of the United States had an ASD. Although accurate for the areas studied, more research is needed before this rate can be generalized to all parts of the US.

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? And 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 was of critical importance, and no names or other identifying information will be collected. Parents will not — and *cannot* — be contacted because a diagnostician has registered their child's condition.

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

The law that initiated the NH Registry for ASD was first put forward by parents through the Autism Society of New Hampshire and other advocacy groups. Until recently, ASD was thought to be a low incidence condition. Promising initiatives like the federal Combating Autism Act of 2006 signal a growing recognition of the impact of this condition upon individuals, families and society as a whole. However, additional information and effort are needed to improve our knowledge about ASD, shape appropriate policy and practices, and obtain funding. The NH Registry will help our state to make progress in these areas and ultimately improve services and supports for individuals with ASD.



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