

## 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 new diagnoses 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 individuals affected by ASD and their families.

### **THE NH REGISTRY FOR AUTISM SPECTRUM DISORDERS**

NH Dept. of Health & Human Services  
Bureau of Developmental Services  
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For Questions about accessing the Registry,  
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## 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](http://www.dhhs.state.nh.us/dhhs/bds)



# 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 online 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 Syndrome, 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 can be found at [www.dhhs.state.nh.us/dhhs/bds](http://www.dhhs.state.nh.us/dhhs/bds).

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## 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 is 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.

The Registry is located at [www.dhhs.state.nh.us/dhhs/bds](http://www.dhhs.state.nh.us/dhhs/bds)