

THE NH REGISTRY FOR AUTISM SPECTRUM DISORDERS



Frequently Asked Questions For Families

Q. What is a registry?

- A.** A registry is an organized system for the collection, storage, retrieval, analysis, and dissemination of information on individuals who have a particular disease, a condition (e.g., a risk factor) that predisposes to the occurrence of a health-related event, or prior exposure to substances (or circumstances) known or suspected to cause adverse health effects. There are registries for many diseases, conditions and events (i.e. cancer, lead poisoning, influenza and birth defects including Down's syndrome). Without these registries, it would be impossible to understand the magnitude of a health problem and its impact on the public.

Additionally, information about when a diagnosis is made and by what type of medical professional can help policy makers understand the ways in which health systems are meeting important goals. For example, the age of diagnosis – and therefore the beginning of medically necessary treatment – is an important predictor of improved outcomes for children with ASD. Many professionals concerned with children's health in NH are not only interested in how many children are being diagnosed with ASD in our state, but at what age clinicians are typically making a confirmed diagnosis and whether there are regional or other differences in the average age of diagnosis.

Q. Why is there a need for a registry for Autism Spectrum Disorders?

- A.** There are a number of registries for ASD throughout the United States. Most are affiliated with an effort by the Centers for Disease Control to pinpoint the prevalence of ASD – that is, how common this health condition is in the general population – and whether this rate is increasing. These registries track the number of children diagnosed on the spectrum at the age of eight years within a specific area, usually several counties of a participating state.

New Hampshire has taken a slightly different approach. The NH Registry for ASD it is designed to answer three important questions:

- ❖ How many individuals are diagnosed each year in NH, regardless of age?
- ❖ 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, are there patterns that tell us more about how NH families access early developmental screening and evaluation.

While the NH Registry will contribute to our understanding of the prevalence of ASD in NH, the primary focus is on assessing whether early identification, screening, and ultimately diagnosis are taking place throughout NH. The information collected by the NH Registry will help policy makers to understand where there may be gaps in NH's system for screening and diagnosing children with apparent developmental delays that may be indicative of ASD.

Q. How common are Autism Spectrum Disorders?

We really do not know how many people in the United States, or in New Hampshire, have an autism spectrum disorder. In 2007, the Centers for Disease Control released data that found about 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.

Q. How does the NH Registry help individuals with autism and their families?

- A.** The law that initiated the NH Registry for ASD was initiated by parents through the Autism Society of New Hampshire and other advocacy groups. Until recently, autism and related conditions were thought to be relatively rare. While promising initiatives like the Combating Autism Act of 2006 signal a recognition of this important issue at the federal level, funding for both research and treatment continue to lag behind that appropriated for many other, less common, conditions. Data from the NH Registry will have an impact on federal and state efforts regarding education in public schools, developmental services, community mental health, vocational supports and even insurance coverage.

Q. Are there other ways to find out how many people have autism and if it is increasing?

- A.** Yes, tracking (also called surveillance) programs can show how many people in a defined population and geographic area have a condition at a given time. For example, the CDC studied how many 3 to 10 year olds in metro Atlanta had autism in the calendar year 1996. They found that 34 in 10,000 had the disorder (significantly higher than the previously reported prevalence rate of 5 in 10,000). This alarming difference caught the attention of the U.S. Congress who charged the CDC with the task of providing collaborative agreements to other states to conduct similar monitoring systems.

However, the multiple sources monitoring system used in the CDC study is extremely labor intensive and can be costly over time. The same method must be implemented in subsequent years to look at any trends. For this reason, over time a registry for newly diagnosed cases is a more appropriate and cost effective means of building the necessary database to make well informed public health decisions at the state level.

Q. Will the name of the individual with an autism spectrum disorder appear in the registry?

- A. No. Names are not being collected.** There is no need to know the name of the individual in order to achieve the goals of the NH Registry. We do need to ensure that we do not enter a person twice (for example, if they receive a diagnosis by two or more diagnosticians, as families sometimes seek a second opinion). We are asking the healthcare professional reporting to use a designated standard method of coding each case that will allow the names to remain confidential.

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

- A.** The total number of new cases of ASD diagnosed each year will be shared with a variety of

agencies that need this information for planning services and supports for individuals with ASD. The information will also be broken down (aggregated) by the age of diagnosis, the region in which the child lives, and the type of healthcare professional making the diagnosis. Among the agencies interested in the data collected by the NH Registry are the NH Bureau of Developmental Services, the Department of Education's Office of Special Education, the Bureau of Special Medical Service, and the Bureau of Behavioral Health. Annual results will also be published on this website.

It is important to know that *no individual data will ever be reported*. Any results reported will be across a group of individuals.

Q. Is this ASD registry legal? If an individual receives a diagnosis, does he/she have to be included in this registry?

- A.** Yes, the NH Registry for ASD is legal. Autism Spectrum Disorders are named a reportable condition under the New Hampshire Department of Health and Human Services, Administrative Rules Unit, He-M 501, adopted May 16, 2008. This addition to the rules was mandated by state law RSA 171-A:30, which was adopted by the NH legislature and signed into law by Governor John Lynch in 2006.

Will the families of those in the registry ever be contacted for more information or about participation in research because they are in the registry?

- A. No.** There would be no way to know who to contact. We do not collect name, address or phone number.

Q. How is an individual reported to the NH Registry?

- A.** If a medical doctor, licensed psychologist, or other healthcare provider makes a definitive diagnosis of autistic disorder (autism), pervasive developmental disorder not otherwise specified (PDD-NOS), Asperger Syndrome, Retts Syndrome or childhood disintegrative disorder, that diagnostician completes a short registry report form. The diagnostician indicates what the diagnosis is, the individual's date of birth, the date of the diagnosis, and the individual's NH town of residence.

Q. Are private practice physicians required to report new ASD cases?

- A.** Yes, in compliance with state law RSA 171-A:30 and state administrative rule He-M 501.

Q. If an individual receives an ASD diagnosis from a facility outside of New Hampshire, must that diagnosis be reported to the NH Registry for ASD?

- A. Yes.** Anyone who both resides in New Hampshire and receives a qualifying diagnosis after Nov. 1, 2008 should be reported to the NH Registry for ASD, regardless of where they received the diagnosis. For this reason, the NH Department of Health and Human Services is making every effort to reach out to diagnosticians in border states. Additionally, we would appreciate it if NH primary care physicians report cases where an out-of-state specialist has made the diagnosis. The registry is designed to eliminate duplicate entries, so primary care providers may register a patient without fear that this will corrupt the data.

Q. How can a family be sure that confidentiality will be protected?

- A.** Confidentiality is a *priority*. No names are collected and there is no information that would

enable anyone to trace a reported diagnosis to a specific individual. In addition, the database that stores the registry information is completely secure and requires a pass code for authorized personnel to enter it.

Q. Does the New Hampshire Registry for ASD comply with HIPAA?

A. Yes. Registries are considered *public health authorities* because their duties are mandated by state laws.

Under HIPAA, a “Public Health Authority” is defined as “an agency or authority of the United States, a State or territory, a political subdivision 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 for 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. 164.501

(2) C.F.R. 164.512