



Frequently Asked Questions For Diagnosticians

Q. Why was the NH Registry for ASD instituted?

- A.** The NH Registry for ASD was developed to help public policy makers in our state anticipate the needs of this apparently growing population, track the effect of improvement strategies aimed at lowering the average age of diagnosis, and better understand the magnitude of this public health issue.

Additionally, in May 2008, the NH Commission on Autism Spectrum Disorders released their **Findings and Recommendations**. The Commission outlined a number of ways in which the system of care for those with ASD must be improved. In order to successfully compete for federal and other funds to assist in implementing the Commission's State Plan, data collection on the scale implemented by the NH Registry is crucial.

Q. How much paperwork is involved in registering a new diagnosis?

Recognizing that diagnosticians must already balance many demands on their time, every effort has been made to keep the paperwork for the NH Registry for ASD to a minimum. This issue was discussed with the NH Medical Association and the NH State Board of Mental Health Practice, both of which reviewed the protocol and made a number of suggestions that were subsequently incorporated into the NH Registry. The Diagnostician Reporting Form can be completed online by support personnel and should take under five minutes to complete.¹

Q. If a child has failed a standard screening tool -- for example, the M-CHAT -- and been referred for further evaluation by a child development specialist, should I register that child?

- A. No.** A Diagnostician Reporting Form should only be filed when and if a *definitive* diagnosis has been made. The diagnostician making the determination – in this example, the specialist – is responsible for registering the child. However, it is important to know that the system is designed to identify duplicate registrations should two physicians file Diagnostician Reporting Forms.

Q. I have referred a child to an out-of-state specialist for further evaluation. If this specialist finds that my patient has an autism spectrum disorder, who files the diagnostician reporting form?

- A.** This is a situation where there is likely to be some confusion. As the primary care provider, you have two choices: You may provide a brochure and form to the out-of-state specialist as part of your referral, asking him or her to register the case if a definitive diagnosis is made; or you may wait for the results of the evaluation and register the diagnosis yourself when you receive the

specialist's report. Again, it is important to know that the system is designed to identify duplicate registrations, so there is no harm in filing a Diagnostician Reporting Form even when you have asked an out-of-state colleague to do so as well.

Q. I have a new patient who was diagnosed with an autism spectrum disorder in their previous state of residence. Should I register this patient?

A. No. Only patients who live in NH at the time of diagnosis are to be registered.

Q. I am a licensed clinical psychologist and see many young adults in my NH practice. I have recently diagnosed a patient with Asperger Syndrome. He is 26 years old and has not been previously diagnosed with this condition. Am I required to register this diagnosis?

A. Yes. The NH Registry for ASD collects all new diagnoses, regardless of the age of the patient, provided the individual is a NH resident at the time the diagnosis was made.

Q. Is the NH Registry for ASD affiliated with any CDC monitoring project?

A. No. The NH Registry is not a participant in current CDC monitoring projects, nor is it funded by the CDC. The goals of the NH Registry are more extensive than current CDC projects, which are primarily aimed at tracking the prevalence of ASD over time. While the NH Registry will contribute to our understanding of the prevalence of ASD in NH, it is also designed to identify and follow patterns in the average age of diagnosis, regional access to diagnostic evaluation, and the types of healthcare professionals making diagnoses in NH.

Q. How is the NH Registry different from the CDC's ADDM Network?

A. The Autism and Developmental Disabilities (ADDM) Network is a multi-site monitoring project sponsored by the CDC. Currently, 17 states participate in the ADDM network. New Hampshire is not among them. ADDM participants register children with ASD -- and in some cases other developmental disabilities -- at the age of eight years. The recommended protocol for the ADDM Network is more detailed than the NH Registry for ASD. Because protecting the privacy of NH citizens was a high priority, the clinicians and family members that developed the NH Diagnostician Form chose not to use the ADDM Network protocol.

Q. What are the implications under HIIPPA of sharing health-related information with the NH Registry?

A. HIPAA does not obstruct any state law that supports or mandates the reporting of diseases or injury for public health purposes. A physician, psychologist, or health care provider who gives information to the Department of Health and Human Services shall not be deemed to be, or held liable for, divulging confidential information. Moreover, the information shared does not include the name of the patient or other details that could identify the individual.