



New Jersey Autism Registry: Q&A for Health Care Providers

How will the registry be used?

The registry will help improve current knowledge and understanding of autism, allow us to conduct thorough and complete epidemiologic surveys of autism, enable analysis of this problem and help plan for and provide services to children and families affected by autism.

Who is required to report?

As of 2007, the registry requires that all health care professionals licensed pursuant to Title 45 of the Revised Statutes register any person from birth through twenty one years of age who is a resident of New Jersey and diagnosed with Autism whom they have either diagnosed or are following for care.

How do I register a child?

Hospitals and other facilities are able to register electronically through a web-based system. Other providers are able to register but mailing or faxing the registrations to the Department of Health. The registration forms are available on our website at http://www.state.nj.us/health/fhs/sch/ar_for_hcp.shtml.

How is Autism defined?

Autism includes the diagnoses commonly known as the Autism Spectrum Disorders that includes Asperger Syndrome, Autistic Disorder, and Pervasive Developmental Disorder Not Otherwise Specified; and the Pervasive Developmental Disorders including Rett Syndrome and Childhood Disintegrative Disorder.

Are Parents contacted?

Yes. Once a child is registered, a letter and informational pamphlets are sent to the parent or legal guardian named on the registration, notifying them that the child has been registered. The county-based Special Child Health Services Case Management Unit will also contact each family to offer access to family-centered coordinated services as well as refer the child to the New Jersey Early Intervention System which provides services for young children with special needs, aged birth to three years, under Part C of the Individuals with Disabilities Education Act.

Can Parents say *No* to having their children registered?

No, all children must be reported by the health care professionals, but families can request an anonymous registration. Providers are still required to report non-identifying information about the child such as their sex and county of residence; the family would not be able to be linked to important services and resources without the child's identifying information.

How is personal information kept confidential?

Recognizing the importance of protecting the person's privacy and confidentiality, the Department will not include any identifying personal information in any reports. The Department will require that all research using the registry be approved by the Department's Institutional Review Board, and fully comply with the Health Insurance Portability and Accountability Act.