

- The health care provider must obtain a signed written statement from the parent and make that statement part of the child's permanent medical record.
- Families who refuse identifying information will not be linked automatically to important services and resources.

Why is the New Jersey Autism Registry important and why should children be registered?

Over the last several years there has been an increase in the number of children diagnosed with Autism. While we don't know the reasons for this increase, we also don't know how many more children are being diagnosed and need services. To best serve individuals, we need to know the number of children being diagnosed and how to reach them so they can be referred to the services they need.

Knowing the number of children with Autism will also allow us to better understand the extent of Autism in New Jersey, allow us to conduct thorough and complete epidemiologic surveillance of Autism, enable us to analyze needs, and help plan for and provide services to children and families affected by Autism.

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 report. We recognize the sensitivity of the information we collect and respect the rights of individuals with Autism and their families. We take seriously our obligation to protect the privacy and confidentiality of this information.

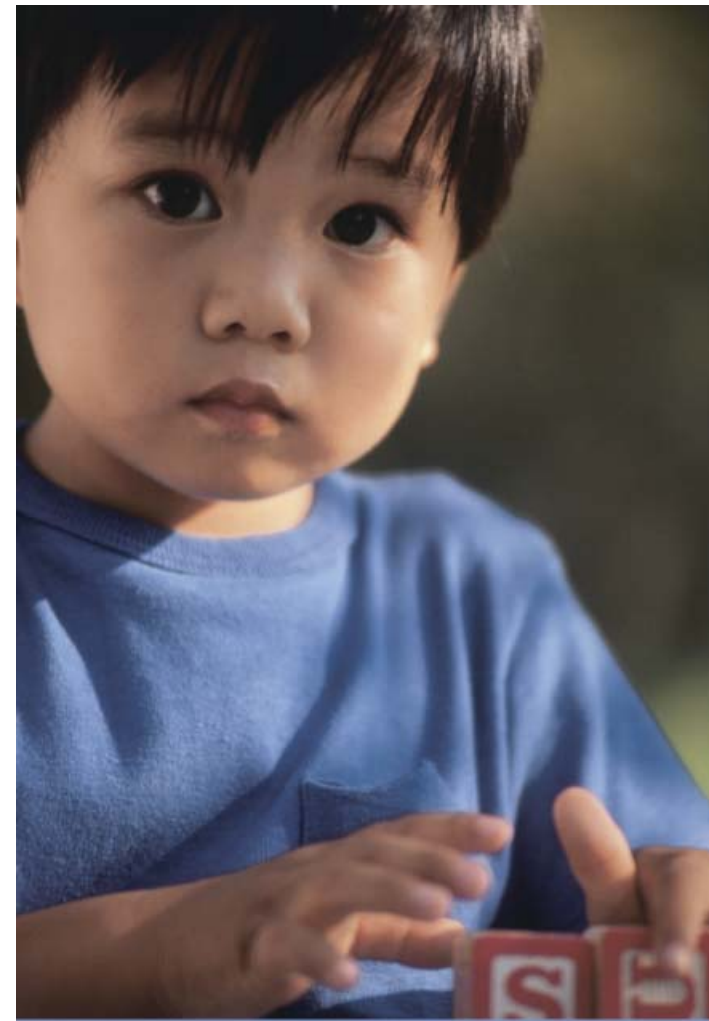


Registration forms are available at:
<http://www.state.nj.us/health/fhs/sch/schr.shtml>

For questions about the registry, please call:
609-292-5676

For information about services available to New Jersey children with special needs go to:
<http://www.state.nj.us/health/fhs/sch/index.shtml>
 OR call: 609-777-7778

**The Autism Registry is part of the
 New Jersey Department of Health & Senior
 Services
 Division of Family Health Services
 Special Child Health and Early Intervention
 Services
 PO Box 364
 Trenton, NJ 08625-0364**



**The New Jersey
 Autism Registry:
 Information for Providers**



**Chris Christie
 Governor
 Kim Guadagno
 Lt. Governor**



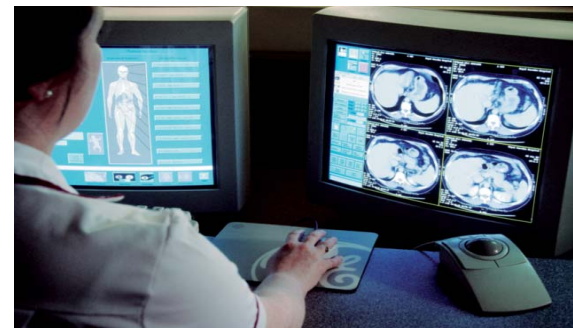
**Mary E. O'Dowd, M.P.H.
 Commissioner**



In 2007, the New Jersey State Legislature and Governor Corzine enacted a law that requires the Department of Health and Senior Services to maintain a registry of individuals diagnosed with Autism. New Jersey health care professionals licensed pursuant to Title 45 of the Revised Statutes are required to register any child that they serve who has or meets the criteria for a diagnosis of Autism, is under the age of twenty-two, and is a New Jersey resident.

How is Autism defined?

In the registry, Autism refers to diagnoses commonly known as the Autism Spectrum Disorders (ASD), which includes Asperger Syndrome, Autistic Disorder, and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS), as well as Rett Syndrome and Childhood Disintegrative Disorder.



How do I register children?

Licensed health care professionals shall register any child whom they have diagnosed with Autism, or follow (previously diagnosed with Autism). You must notify parents of the registration process. To register a child, complete the SCH-0 and SCH-1 forms found on the Department website at:

<http://www.state.nj.us/health/fhs/sch/schr.shtml>.

and mail the completed forms to:

New Jersey Department of Health and Senior Services
Special Child Health and Early Intervention Services
Early Identification and Monitoring/Autism Registry
PO Box 364
Trenton, New Jersey 08625-0364.

Or, you can submit the information electronically through the Birth Defects and Autism Reporting System. To obtain access to the electronic Birth Defects and Autism Reporting System contact the Department of Health and Senior Service's Special Child Health and Early Intervention Services at (609) 292-5676.

What information will be collected?

The registry is collecting the following information:

- Child's demographics such as the date of birth, gender, and race
- Contact information such as name and address of the child and parent
- Diagnosis and diagnostic tools used to evaluate the child
- Diagnostician and the person submitting the form

Why are names and personal identification being collected?

There are many reasons why identifying information is collected in the registry.

- The purpose of the registry is to refer children with special needs to services in their community.
- Without this information we would not know if children were previously registered, and therefore they could be counted multiple times.
- If a child's diagnosis changes, providers will need to submit a revised registration to the Department so that it can be updated.

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 their child has been registered and giving them information on services available. Families are then linked to the Special Child Health Services Case Management Unit in their county.

Can parents refuse to allow their child to be registered?

No, but families can ask not to include personally identifying information about the child such as their name and address. In this situation:

- Health care professionals must still report non-identifying information such as sex, month and year of birth, and county of residence.