

New Jersey Autism Registry

How private is my child's information?

We recognize the sensitivity of your information and respect the rights of all individuals with autism and their families. We take our obligation to protect the privacy and confidentiality of individuals seriously and we keep all personal information in a secured location.



Does my child have to be registered?

Yes, by law, health care professionals need to register children diagnosed with autism. You can ask your health care professional not to include your child's personal information such as their name and address on the registration form.

However, if your child's personal information is not included:

- ❖ We will not be able to link your child to important services and resources, or your county-based case management unit
- ❖ Your health care provider will need a signed written statement from you for their files
- ❖ Your child's non-identifying information such as sex, month and year of birth, and county of residence will still be registered



For questions about the Autism Registry, please call:

609-292-5676

or

visit our website at:

<http://nj.gov/health/fhs/autism/public/registry/>

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



New Jersey Autism Registry

What is Autism?

Autism is a condition that affects a child's development and function in social interactions, communication, and patterns of behavior. In the New Jersey Autism Registry, we include Autism Spectrum Disorder (ASD) and if previously diagnosed with the DSM IV, Asperger Syndrome, Autistic Disorder, and Pervasive Developmental Disorder – Not Otherwise Specified. If your child has been diagnosed with one of these conditions your child will be included in the registry.



How will my child be registered?

Your health care provider will register your child by completing specific forms and submitting them to the Autism Registry. Only children who are New Jersey residents and under the age of 22 will be registered.

Your provider must inform you about the registry. If you are unsure if your child has been registered and would like to have your child registered, please contact your health care provider.



What information about my child will be reported to the registry?

The registry collects information such as:

- ❖ Your child's name, address, date of birth, gender, and race
- ❖ Your child's diagnosis, when you first noticed symptoms, and when they were diagnosed
- ❖ Information about the provider who made the diagnosis

Why is my child's name and personal information being collected?

Personal information is collected so that:

- ❖ You can be referred to the Special Child Health Services Case Management Unit in your county for help with resources
- ❖ Having named registration information ensures that each child is counted only once



Will I be contacted?

Yes. Once your child is registered you will receive a letter telling you that your child has been registered and information about services that may be available to you and your family.



Your county's Special Child Health Services Case Manager will contact your family to review comprehensive, coordinated, family-centered services. Case Management is voluntary, free and is available for children birth through 21 years of age.

Why should my child be registered?

Over the last several years there has been an increase in the number of children diagnosed with Autism. To best serve children with autism, we need to know how many children are being diagnosed so that we can plan and provide services for them and their families. It's important that your child be registered, so that your family can be notified of these services, some at no charge to the families.

