



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 seriously our obligation to protect

the privacy and confidentiality of individuals and we keep all personal information in a tightly secured location.

Can you refuse to have your child registered?

No, but 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 Registry, please call:
609-292-5676

If you need services, visit our website at:
<http://www.state.nj.us/health/fhs/sch/index.shtml>
or

- ❖ For children birth to age three with developmental delays and disabilities, please call 1-888-653-4463
- ❖ For children birth through age 21 with special health care needs, each county's telephone number can be found on our website:
<http://www.nj.gov/health/fhs/sch/sccase.shtml>
or by calling 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 Families**



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



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

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 diagnoses commonly

known as the Autism Spectrum Disorders (ASD). These include Asperger Syndrome, Autistic Disorder, and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS), Rett Syndrome and Childhood Disintegrative Disorder. If your child has been diagnosed with one of these conditions they are 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 Department of Health and Senior Services. Only children who are New Jersey residents and under the age of twenty-two 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 will be collecting 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.
- If your child's information or diagnosis changes, we are able to update the registry.

Will I be contacted?

Yes. Once your child is registered, you will receive a letter and informational pamphlets telling you that your child has been registered, and about services that may be available for you and your family.

A person from your county's Special Child Health Services Case Management Unit will contact your family and inform you of available family-centered services in your community. County-based case management units assist families of children from birth to 21 years of age with special health care needs.

Why should my child 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 children with Autism, we need to know how many children are being diagnosed so that we can plan and provide services to them and their families. It's important that your child be registered, so that your family can be notified of these services, many at no charge to the families.

