

Why is the WVASDR important?

There has been increased attention on the prevalence and incidence of autism spectrum disorders in the United States. Studies from California, have suggested an increase of 273% from 1987 to 1998. This alarming increase captured the attention of national media and the United States Congress. In 2001, Congressman Chris Smith (R-New Jersey) stated "it is not an exaggeration to say that autism spectrum disorders may be the silent epidemic of our time....It is silent because there are currently no operational autism registries in the nation to tell us how many people actually have autism." West Virginia is the first state in the nation to establish a legislatively mandated autism spectrum disorders registry. As other states follow with similar autism spectrum disorder registry procedures, our combined efforts will help us understand more about the incidence of this most challenging syndrome.



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West Virginia Autism Spectrum Disorders Registry

HOUSED AND MANAGED BY:

**THE WEST VIRGINIA AUTISM
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West Virginia Autism Spectrum Disorders Registry

What are the eligibility requirements for the West Virginia Autism Spectrum Disorders Registry (WVASDR)?

Autism spectrum disorders, for purposes of this Registry, include: Autistic Disorder, Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS), Asperger's Disorder, Rett's Disorder, and Childhood Disintegrative Disorder (CDD). The primary and *confirmed* diagnosis must be one of these five disorders, as per the Diagnostic & Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR). The person with the disorder must also live in the state of West Virginia to be considered for the WVASDR.

How common are autism spectrum disorders ?

Although we do not know the prevalence rate of autism spectrum disorders in every community in the United States, the most recent data are from metropolitan Atlanta where the rate was found to be 3.4 per 1,000 3 to 10 year old children*. The prevalence rate was 4 times higher in boys than in girls.

*M. Yeargin-Allsopp, C. Rice, T. Kavapukar, N. Doernberg, C. Boyle, C. Murphy, (2003)

What is the West Virginia Autism Spectrum Disorders Registry?

The West Virginia Autism Spectrum Disorders Registry (WVASDR) began January 1, 2004. Autism spectrum disorders are reportable conditions of childhood (Legislative Rule 64, series 7, category 11A) (3.5.b.2). The WVASDR is housed and managed by the West Virginia Autism Training Center, at Marshall University, as per the protocol in the legislative rule. The WVASDR will allow us to track the number of West Virginians diagnosed with an autism spectrum disorder each year.

We are well aware of the sensitivity of the information we collect and are mindful that it represents the lives of persons with autism spectrum disorders. Accordingly, we practice strict confidentiality procedures and are in complete compliance with the Health Information Portability and Accountability Act of 1996 (HIPAA).

Who Reports to the WVASDR?

Reporting to the WVASDR is mandatory for neurologists, pediatricians, family physicians, psychiatrists, and clinical psychologists.

How are autism spectrum disorders reported?

All reporting entities have one month, from the day of diagnosis, to report an autism spectrum disorder to the WVASDR, at the West Virginia Autism Training Center, Marshall University.

Reporting Forms & Information

Reporting forms can be obtained through the WVASDR website at www.marshall.edu/wvasdr, or by contacting Cathy Jo Templeton, the WVASDR Coordinator, at 1-800-344-5115 (In WV) (304) 696-2332

