

What do the new numbers for autism mean?

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We were all shocked to get the new numbers from the Centers for Disease Control and Prevention: About one in every 88 eight year olds has been identified with an autism spectrum disorder (ASD). The rate for boys is one in 54.

What do these numbers mean for Delaware?

Staff spent some time reviewing public information in an attempt to estimate how many Delawareans have autism. This was not an easy process. We cannot assume that the one-in-88 prevalence crosses all ages, so we did not project numbers based on census data. Instead, we looked at public information reported by the Department of Education (DOE) and the Delaware Division of Developmental Disabilities Services (DDDS) and then developed a conservative estimate: 1,300 Delawareans have ASDs. (For more, visit www.delautism.org, and click on About Autism and Statistics & Studies.) We suspect this number is probably higher.

Why do we think our number is conservative?

The DOE and DDDS figures do not include children attending private schools or being home-schooled. The figures also exclude individuals of any age who have not registered for or used state services. The figures further exclude adults who never received services or who may be misdiagnosed. While diagnoses for children with classic autism have improved significantly, adults with ASDs are more likely to be misdiagnosed.

Appropriate diagnosis for individuals with Asperger's syndrome is even more problematic. Asperger's is considered a relatively new disability. It wasn't even known in the U.S. until Hans Asperger's work was translated into English and incorporated into the World Health Organization's diagnostic manual and the *Diagnostic and Statistical Manual of Mental Disorders* (DSM) in the early 1990s. Only in the past 10 years has Asperger's syndrome become more commonly understood; thus, we have generations of psychologists, psychiatrists, teachers, and school counselors who have not been trained to recognize and treat Asperger's syndrome.

So what does the increase in numbers mean?

It means an increasing impact on all systems (publicly funded services across different agencies)—and the need for advocacy to jump to the top of the priority list. Children still need to leave school with the practical and social skills to navigate the adult world of work and relationships. With more children needing these skills, systems must be using evidence-based practices and expanding their capacity to serve children and adults across the spectrum through better staff education and training. And the schools should ensure that students either graduate into jobs or are prepared to meet the challenges of post-secondary education.

We also need services and agencies to collaborate more effectively with each other so that the individual living with autism may have access to social services, mental health services, housing, independent living, and whatever else he or she needs. After all, people with diabetes go to diabetes specialists—not the DD case manager. Why shouldn't people with autism seek mental health services from mental health agencies?

In sum, our job as advocates is to expand not only the capacity of Delaware's systems to better meet the needs of people living with ASDs, but also to expand to meet the growing population and the growing need. The future of our children depends on it.



Helping People and Families Affected by Autism

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